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CHILDREN'S PRIMARY CARE AND CHRONIC HEALTH CARE ISSUES

HEARINGS

BEFORE THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

SECOND SESSION

MAY 24 AND 26, 1988

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CHILDREN'S PRIMARY CARE AND CHRONIC HEALTH CARE ISSUES

TUESDAY, MAY 24, 1988

U.S. Senate,
Committee on Finance,
Washington, DC.

The hearing was convened, pursuant to notice, at 10:27 a.m. in Room SD-215, Dirksen Senate Office Building, the Honorable Lloyd Bentsen (Chairman) presiding.

Present: Senators Bentsen, Baucus, Bradley, Daschle, Roth, Danforth, Chafee, Heinz, and Durenberger.

[The prepared statements of Senators Bentsen, Durenberger and Chafee appear in the Appendix.]

[The press release announcing the hearing follows:]

[Press Release No. H-17, April 20, 1988]

Bentsen Announces Finance Committee Hearings on Children's Health Care Issues

Washington, DC.—Senator Lloyd Bentsen, (D., Texas), Chairman, announced Monday that the Senate Finance Committee will hold two hearings on issues pertaining to children's health care. The first will focus on primary care and the second on children who require costly medical care.

The hearing on primary care is scheduled for *Tuesday, May 24, 1988 at 10:00 a.m.*, and the hearing on chronic illnesses will be held on *Thursday, May 26, 1988 at 10:00 a.m.*, both to take place in Room SD-215 of the Dirksen Senate Office Building.

Bentsen said, "There is ample evidence that investing in primary care and prevention of illness can pay off handsomely for children, their families and the Nation. The primary care hearing will help us develop strategies to improve children's health care, particularly strategies to turn around the disturbing lack of progress in improving infant mortality rates."

On the hearing for chronically ill children, Bentsen said, "When a child is struck with a high-cost illness, his or her family bears not only the emotional burden, but also faces the prospect of financial ruin when public and private resources prove inadequate. This hearing will focus on proposals for improving the complex and fragmented approaches currently in place for financing and delivering care to children with serious illnesses."

OPENING STATEMENT OF HON. LLOYD BENTSEN, A U.S. SENATOR FROM TEXAS, CHAIRMAN, SENATE FINANCE COMMITTEE

The Chairman. This hearing will come to order.

I apologize for the lateness in start, but we had a conflict in our committee markups this morning—too many at the same time.

This morning we are holding the second in a series of hearings on health care policies affecting children. Today's hearings will focus on issues related to primary care services, including a reduction of infant mortality rates, maternal and child health, and other special concerns.

There is a great deal of interest among members of this committee on these issues, and I hope that this morning's hearings will generate a continuing discussion of how best to guarantee our children a healthy start in life and access to basic health care services.

Later this morning Senator Chiles will be joining us to comment upon the work of the National Commission on Infant Mortality, which he so ably chaired for the last year.

Last fall, when I introduced legislation to create a National Commission on Children, I indicated that I hoped to make the year 1968 the year during which child health care issues would become a priority agenda item for the Senate Finance Committee.

The Infant Mortality Commission has done a fine job of laying the groundwork for the work of the Children's Commission.

It is well known to members of this committee that, as a Nation, a lot more has to be done to improve basic health care for our children. Let me give you some of the numbers to put it into perspective:

The United States ranks seventeenth among developed countries of the world in infant mortality rate—seventeenth. We have made no progress in this area at all since 1985.

A white infant born in this country is two-thirds more likely to die in his first year than a baby born in Japan. A black baby born here in Washington, or in many of the Nation's other cities, is more likely to die before his first birthday than a baby born in Jamaica.

The Guttmacher Institute, from whom we will be hearing today, recently reported that as many as 35 percent of American pregnant women get less than sufficient prenatal health care. That is despite the evidence that investments in prenatal care are returned three to one during the first year of the infant's life.

You know, if you have the toughest, the hardest of fiscal conservatives, if you are not concerned about the emotions or the well-being but just dollars to the Treasury—three to one, of the taxpayers' money coming back.

At our first hearing on this subject in March, we heard from the Office of Technology Assessment that the United States is not doing as well as it could in preventing health problems in children. The OTA reminds us that preventing or treating health care problems in early childhood can benefit a child for a lifetime, that investing in improvements can pay off handsomely by guaranteeing us that the next generation be healthy, productive adults.

We also know that some American children, those from low income families and those with limited access to health insurance, are a particularly high risk.

Now, today we are going to hear from a broad spectrum of witnesses about strategies to improve access to primary care services for children. Sure, there are some success stories to be told.

On the other hand, we have much farther to go to assure that all children have access to adequate and affordable health care. What we are really striving for is to have children, to the extent possible, born with healthy bodies and healthy minds.

Failure to grapple with those problems faced by children and their families is going to shortchange this country of the strong and healthy leaders that we need in the next generation.

There is no one more aware than I of the difficulty of improving child health programs in a time of budget constraints, but we shouldn't be deterred from a task that both compassion and cost effectiveness tell us is in demand.

Senator Chiles, I was commenting on the work that you have done in this past year, chairing that commission, and why don't we hear from you now, if you would come forward, please.

Senator CHILES. Thank you very much, Mr. Chairman.

OPENING STATEMENT OF HON. DAVE DURENBERGER, A U.S. SENATOR FROM MINNESOTA

Senator DURENBERGER. Mr. Chairman, could I make just a brief statement before he begins?

The CHAIRMAN. By all means. I defer to my colleague on the committee, Senator Durenberger.

Senator DURENBERGER. Thank you very much.

Two of us who are down at the end of this table have remarked frequently about how far we are from those of you at the center of this table, and how long we have been in this position—10 years, as I recall.

(Laughter)

The CHAIRMAN. Well, that is the stability of this committee, which I am all for.

(Laughter)

Senator DURENBERGER. I can appreciate your bias, Mr. Chairman.

Really, on behalf of all who aren't here, I will say what everyone would say about the Chairman, and that is that his leadership in the area of child health is well known to all of us on this committee. And as we have come on this committee, we have all been exposed to Lloyd Bentsen's commitment to children.

I thought maybe he misspoke a little while ago when he said he wanted 1968 to be the Year of the Child, and he really meant 1988; but he also probably meant 1968 and 1978 and 1958, and all the rest of those years.

(Laughter)

The CHAIRMAN. I have been on this track a long time.

Senator DURENBERGER. Yes. And that is about how long, or longer, that you have been trying to make it the Year of the Child. I think in 1988 you have succeeded. My magazine says you have succeeded, and a whole lot of other places say you have succeeded, at least in making it the Year of the Child.

The question now is what the rest of us do about it here in this country. The work you have done on the Catastrophic Illness Protection Act to ensure that infants and pregnant women whose family incomes are below the poverty level will be guaranteed access to prenatal, newborn care, and delivery services needs to be recognized by the country.

We need also to recognize that all pregnant women and children must have access to health, nutrition, and other child protection services that are essential for life, and that is what this hearing is all about.

But more than anything else, my experience with our colleague from Florida, both at getting the Infant Mortality Commission Bill passed in 1986 and in the work that he has done as Chair of this committee, Mr. Chairman, in the last year and a half, has led me to believe that unless everybody in this country decides that children are national treasures, and we start treating them that way, we really aren't going to get this job done. There are too many other more vocal priorities in America that take us constantly away from the notion that we are lagging in our care for children.

So it seems to me that some kind of a commitment needs to be made by this country, specifically to the unique nature of a child in our society. Until we do that, we aren't going to be able to address adequately the Maternal and Child Health, or prenatal care, or child care, or early childhood development, or any of the other educational and health care needs that we have.

I think that is your objective, just making a commitment to kids in this country, and then all the other strategies can flow from that; but you can't do these things in isolation, you can't just do Medicaid today and Head Start someplace else, and child care in another place. You really need to begin with a commitment, and I am pleased to see you here today.

I wanted you to know that out in Minnesota there are lots of organizations with this commitment. Here is an organization called "Good Health is Good Business," and we have all kinds of folks in our constituencies that are committed to this. They are sort of waiting on us, I think, to make sure that national policy points in the same direction that they have pointed their organizations.

The CHAIRMAN. Senator, you are very generous in your statement. Let me state that your State is a leader in this effort, and you are a leader of your State. The contribution you have made on this issue time and time again has been extremely productive and helpful, and I have been much pleased and appreciative of the kind of support you have given in this effort.

Senator Chiles, we are pleased to have you this morning and know of your long-term commitment in this effort and what you have been able to accomplish.

Although you didn't clear your decision about leaving here with some of us, you will have left a major imprint here, my friend, and if you will proceed, we are delighted to have you.

OPENING STATEMENT OF HON. LAWTON CHILES, A U.S. SENATOR FROM FLORIDA

Senator CHILES. I thank you very much.

As you have noted, I have become a little more bold in some of my outlooks, now that I am going to leave the problem to someone else.

(Laughter)

Senator CHILES. I want to say at the outset that I am so pleased to see the tremendous leadership and interest that you have shown and are showing in this, and I know that you will continue to follow up. There is just something about us grandfathers, I think some of our experience helps get our attention, helps us understand, and perhaps some of those years help us become more cognizant of what are some of the real important things for this country. Your leadership has been so great in that.

And Senator Durenberger was a cosponsor of the legislation to create the Commission and serves as a member on it. We know of his great work in this.

It has been an interesting experience for me during this year. We set up the Commission as a one-year commission to try to develop a strategy to reduce infant mortality and to put it in perspective.

Again, not so much as for you, because you do know, but for our audience and for the record, we remind them that 40,000 babies die every year in the United States before their first birthday. That is the same number of people, roughly, that we are losing from AIDS. We are now going to spend upwards of a billion and a half dollars this year on AIDS, and we have raised that in the last two or three years from a couple of hundred million to that sum, because we have everybody's attention in AIDS, and we understand how great a problem it is.

We are losing five babies every hour, every day. It is, again, about the same number of men that we lost in the entire war in Vietnam. And those deaths are just the tip of the iceberg, because even more live with physical or emotional disabilities that take their toll, both in human and fiscal terms. They could be spared their tragedies, and their families could, if we could simply refocus our nation's priorities to better promote the health and welfare of mothers and infants.

One of the important things that I learned on the Commission is that we have got to change the American mindset about the problem. It is not that we lack the knowhow to have babies born healthy; we know how to do that better than any nation in the world. What we really lack is a sense of priority, of the national importance, to the steps that have to be taken to assure that each baby is given the best start in life.

As I have gone around the country with the Commission I have been surprised to find out how little our people really do know about it. They assume that, in this great country of ours, our mothers and babies are being cared for. After all, this is the USA, home of Norman Rockwell and all those great paintings we have seen of babies being kissed by politicians and pushed on swings in neighborhood parks. But we know that there are some differences in those images.

Also, I think people in this country know about our tremendous medical progress. We save so many of these low birthweight babies now that we previously couldn't save. Our progress has been in our technology and in our doctors. But we are not providing front-end care. We are not giving that expectant mother nutrition advice nor food if she needs it. She often cannot obtain medical screening. All of these things at the front end.

We had a hearing that we held at the U.N., and we asked some of our neighboring countries how they care for their mothers and babies. Just to remind you, we are nineteenth among industrialized nations in infant mortality. If a child was born today in Singapore or Hong Kong, he would have a better chance of reaching his first birthday than if born in the United States.

When you tell that to people, they find it shocking. They can't believe it. But when you find that in Belgium and in France and in the Netherlands, and in all of those countries where they just beat the socks off of us in their percentages, and you ask them about their neonatal facilities and what they have, they don't have them. And yet, their numbers are almost twice as good as ours, because they are having healthy babies to start with and thus do not have to save them with high technology.

We are good at that. We spend a lot of money on it. It costs an average of $150,000 when we have to use "high tech" care. Lawton Chiles IV is the recipient of that kind of treatment. His medical bill was $250-275,000. He was a low birthweight baby, born premature, and a screening device would have shown that, because his grandmother had the same problem. But that happens even in instances where people have adequate medical care.

But what we find is the patterns run hand in hand. If you have a low birthweight baby, you can look at the numbers, and you find in most instances, 60-70-80 percent, the first time that low birthweight, baby's mother gets medical care is when she shows up at the emergency room of the hospital in labor. In other words, it has already started.

That is our biggest problem. In France and some of these other countries and Japan, after the devastation of World War II, they decided that they had to make babies a national priority. So they began to make sure they picked up every pregnant woman, and they gave her a passport. It is a little book, and it says, "Here is what you are entitled to: You are entitled to this kind of care, and we are going to provide that," and they give them special treatment.

In Britain they have nurses that ride around and visit mothers and babies at home...home visits, they visit everyone including the Princess. She got a visit from the Home Visitors to tell her what she could expect.

Mr. Chairman, you are concerned about money, and certainly Senator Durenberger, and I are also. We are talking about something that, in addition to the human suffering thing, makes so much sense from the monetary sense. We are talking about approximately $400 per pregnancy to provide adequate care. That is not the delivery but all of the care up to the delivery to a woman who is pregnant, as opposed to what it is going to cost us and is costing us. It is like the undertaker: "If you don't pay me now, pay me later." We are paying for it as a society, and we will continue to pay for it.

So I think our task is sort of twofold: One is to try to educate the public. And part of our problem is there are counties, cities, areas in which all of these services are available, and expectant mothers don't know about it. There are other places in which they are not available.

We have got to make children a national priority. We have got to convince people of that, and we have got to provide some of those funds at the front end so I think we can make the savings overall.

I have got a more complete statement that I would like to put in the record. I also want to say I am delighted to see your children's Commission. I think it is tremendously, worthwhile, and I want to assist in any way that I can. I assure you that this is an interest that I will continue to have, regardless of the fact that I might not be here. I am delighted to see that you all will continue your interest in it as well.

The CHAIRMAN. Senator, I appreciate that. I have shared some of the same experiences you have as a grandfather insofar as the health problems.

[Senator Chiles' prepared statement appears in the Appendix.]

The CHAIRMAN. I understand that the Infant Mortality Commission may recommend—may recommend—that the States be required to provide prenatal care and infant care to women and babies whose families make below the federal poverty line.

Would you care to comment on that?

Senator CHILES. Mr. Chairman, we are in the process of putting together our report now. It is not finalized, and all of the members have some say; but I think that we are going to try to recognize that part of what the Commission is to do is to state what needs to be done, and to state that clearly, and to try to use that as the thrust.

Certainly, what needs to be done is that every mother in this country is entitled to adequate care. That will be one of the things we will be stressing.

The CHAIRMAN. In your travels did you get into the infant care, the prenatal health care, that is taking place in Japan? They are leading the world today on infant mortality.

Senator CHILES. Yes.

The CHAIRMAN. Is there anything we can learn from them in that regard?

Senator CHILES. Yes, sir. And the biggest thing is that support they give and the honor, in effect, that they place on the pregnant woman. She is given, as I say, a passport that gives her the front seat on the bus, literally, in transportation and all kinds of other areas, and they see that she has the ability to get to the care, and that the care is adequate. And they have a network to pick up all of these pregnancies that are out there and see that they are brought into the system where they are given the care. It is a strong family support, but it is also a strong community and public sector support. It all sort of meshes together, but it starts with this priority that they place on it. It is more that than it is in the medical or technical expertise that they have.

The CHAIRMAN. Well, there is a lot more that has to be done in this country in coordination of effort. I know of an instance in one of the major cities in Texas, where you could have someone going in on Medicaid for prenatal health care, and they would have to go through all of the ritual, the forms, the waiting, and you would have a working mother who didn't have that much time off from her job. After she went through all of the hours of waiting, then when it came time for delivery of the baby she would have to go to a different hospital, and they would put her through the same bloody process again; they did not have the computers tied together. Just this year that has been corrected, but it is those kinds of bureaucratic snafus that add to the problem.

Senator CHILES. Former Governor Riley of South Carolina who sits on our Committee was telling us that the form, the AFDC form that you have to fill out to get AFDC support, is 44 pages, and it is designed to sort of discourage you, or to keep you from getting that. He said that, literally, the way we harp on the errors rate and everything else, the system is designed in the bureaucracy to weed people out, to keep them from completing the form. And that is just one area.

So what we have—we don't have any one-stop services. Now, some communities have put that together, and it is amazing what you see happening.

Part of it is our problem in Congress. Nutritional programs go through the agricultural committees and come through the agricultural budget; some of our services come through Medicaid; some come through this area; and some are funnelled into the States. So we are talking about four or five different stops, many times in different places, each time a different set of forms. All of that is just sort of a maze that is set there.

Mr. Chairman, we had some figures done that showed that if our infant mortality rate was what Japan's was, and that is about half of ours, our savings could be anywhere from $8-13 billion over the lifetime of a set of children by lost earnings and tax revenues that they would pay. So it is something. And that is do-able because Japan has done it. Their numbers were higher than ours, and they reduced their numbers, and in approximately 20 years they went down to where they find themselves now.

The CHAIRMAN. Well, immediately following World War II their numbers were terrible. They have done a very dramatic job.

To defer to my colleague, Senator Durenberger, do you have any questions?

Senator DURENBERGER. Thank you, Mr. Chairman. Just a brief question to my colleague.

It struck me as we were debating, trying to come to some closure on some of the issues in front of the Commission—and we got a little hung up for a while on Medicaid versus other solutions to the problem—it was occurring to me at the time that when we say "Social Security" in this country, we tend to think of old people. In this committee we have the Social Security Act, which covers everything from minus-nine months or earlier all the way to the time of death, and yet, we address children here and there. I mean, there is a little block grant here, and there is a qualification in Title 20, and then there is Title 19, and so forth.

Yet, when you say "Social Security" or you say "social insurance," nobody thinks about young people; nobody thinks about kids, nobody thinks about mothers. The tendency in this country is to think about it as a retirement program, or even a disability program.

I wonder what my colleague's sort of parting thoughts might be about how we might relook as a society at social insurance, so that as we deal with reforms in Title 19, which is Medicaid, or reforms in Medicare, in which we don't pay much attention to the poor or elderly or the chronically ill, or anything else, would we be well advised on this committee to sort of think over a review of the Social Security Act and to focus our thinking in some section of that Act or some title of that Act, to focus on the kinds of problems that we will be hearing about here today.

Senator CHILES. Well, you may be exactly right. But I think one of the ways of focusing on that, whether it is the Social Security Act or how, is that right now I think everybody in this country knows that some years back the Congress decided that all of our elderly people, regardless of their station in life, were entitled to health care, and we were going to provide that care for them.

Now we keep talking about how we broaden that care and whether we now put in—well, I think you all have talked about drugs a little bit lately. I have heard something like that.

The CHAIRMAN. Just a little bit.

Senator DURENBERGER. A little bit.

Senator CHILES. But what other things we will put in.

But everybody knows, in place—and I think that has served this country very, very well—we have not done that about children. We really do not have that. You know, that is not out there.

To me, when that step is taken, and when this Congress and this government goes on record as saying that, then I think some of these attitudes will change.

There is one other thing I wanted to say.

The CHAIRMAN. Do you think if we lowered the voting age to zero we might be able to get some attention to it?

(Laughter)

Senator CHILES. Well, I thought we would get a lot more attention when we lowered the voting age to 18, and I was disappointed in that.

Mr. Chairman, one of other things that we held a hearing on and that I wanted to touch on is the area of the private sector and their responsibilities in this. It is great. And it is interesting to see that it is beginning to dawn on some of our companies how important women in the workplace are and how necessary it is, and what a factor it is going to be, especially as we go into the next 20 and 30 years, and that they need to provide this kind of coverage and service. That is part of our real problem.

This is controversial, whenever you start saying what should be in health insurance policies, or anything. But the fact that companies have not seen fit to make available coverage for this prenatal care is tremendously important.

Some companies have. It is interesting—the ones that have will tell you that their rates have gone down, that they found that 70 percent of their claims came from a smaller percent of the work force, and many of those were where women had these terrible difficulties. So we are talking about something there, again, that makes sound sense.

The CHAIRMAN. Are there further comments? Senator Roth?

OPENING STATEMENT OF HON. WILLIAM V. ROTH, JR., A U.S. SENATOR FROM DELAWARE

Senator ROTH. Mr. Chairman, I missed the presentation by Senator Chiles, but I know he made some reference to Japan. Perhaps the Committee and witness covered the following point.

Do we know what brought about this tremendous change in infant mortality, and what were the key factors in the Japanese policy?

Senator CHILES. Yes, sir.

Senator ROTH. I wonder, would you mind reiterating the policy?

Senator CHILES. They made children "the" national priority. They had been devastated after the war, and they knew that they had to have healthy babies. They made it a national priority.

They identified each pregnancy that they had very early on. They literally sort of gave a "passport" to the pregnant woman telling her what her rights were, making sure that she understood. They provided prenatal care and nutrition, if necessary.

In other words, what was necessary to do they did. It was all done at the front end, and they therefore produced healthy babies to start with.

They still do not have the neonatal facilities that we have; they do not have the elaborate medical settings that we have all around. You know, most of our States have the neonatal clinics, where we can care for these children that are born with low birthweights.

The biggest problem, 70+ percent of the problem, is low birthweight. The baby doesn't weigh enough. That either triggers the premature birth or it is a part of the premature birth, however you want it; and that is, the woman doesn't know she shouldn't smoke, she doesn't know she shouldn't use drugs or alcohol, she doesn't know that she should eat properly.

Those kinds of simple things are what Japan did, and they did it very, very well, and they set up a net to make sure that they caught these people. And then within 20 years, their numbers just turned around dramatically—half of what ours are.

Senator ROTH. I see.

Thank you, Mr. Chairman.

The Chairman. Thank you very much, Senator.

Senator CHILES. Thank you, Mr. Chairman.

The CHAIRMAN. We have two very distinguished panels here. Let us have the first panel. It will be Dr. James Jones, who is President-Elect of the American Academy of Family Physicians of Greenville, North Carolina; Ms. Jean Rosoff, who is the President of the Guttmacher Institute in Washington, D.C.; and Dr. James Perrin, Director of Ambulatory Care Program and General Pediatrics of the Children's Service, Massachusetts General Hospital.

Dr. Jones, would you proceed?

STATEMENT OF JAMES G. JONES, M.D., PRESIDENT-ELECT, THE AMERICAN ACADEMY OF FAMILY PHYSICIANS, GREENVILLE, NC

Dr. JONES. Thank you, Mr. Chairman.

I am Jim Jones, a country doctor from North Carolina, also honored to serve as the President-Elect of the American Academy of Family Physicians.

The Academy represents 60,000 practicing family physicians, medical students, and residents in this country. It is my great pleasure to appear particularly before this distinguished committee.

Mr. Chairman, you and several of the other Senators here have been certainly vitally interested in the health problems of children, and it is my privilege to be able to discuss some of our views on the issues that affect the health of our children.

It is also my hope that the testimony that I will give and that others will give today will help to ensure access of health care to this very vulnerable segment of our population.

As you so eloquently stated in your opening comments, Mr. Chairman, perhaps our most valuable resource are indeed our children.

Most people are familiar with pediatricians and their interest in children of this country. I would like to have the opportunity to also speak to the interest of the family physicians in the health of the children of America.

Family physicians provide ambulatory-based, cost-effective, preventive-oriented health care to a large segment of the population of this country, and in that segment of the population, Mr. Chairman, are significant numbers of children.

Data from the Ambulatory Care Survey of recent years shows that family physicians care for about 20 to 25 percent of the pediatric care given in this country.

Family physicians are very well aware that quality health care provided during pregnancy and early childhood influences the health of the child throughout their lifetime. In no place, Mr. Chairman, is this more true than in teenage pregnancy, which the Academy of Family Physicians has targeted as a major area of interest. It has indeed, in our opinion, reached the state of national embarrassment.

In perhaps no place better than the teenage pregnancy does one understand that good prenatal care is one of the most important factors in a child's development. Timely access to preventive diagnostic and therapeutic prenatal services decreases the likelihood of low birthweight and improves the health of the mother and the baby.

Preventive care during pregnancy increases the likelihood of a healthy baby, and we believe it is cost effective. Prompt medical attention for infants and children is also important.

We worry about the access to immunizations and other proven effective means of health care in children. We believe that family doctors recognize the devastating impact that lack of accessibility to health care is having on children and their families.

Improving access to health care for all Americans is a major goal of the Academy. Promoting and maintaining the health care of children inparticular requires a national effort to strengthen our public programs.

As you have heard already from Senator Chiles and others, the money is well saved because, as the OTA pointed out, of the cost to maintain children of low birthweights throughout the first years of their lives.

The lack of adequate financial resources to purchase basic health care and health insurance is a major impediment to adequate health care for many who, although poor, do not meet the Medicaid eligibility criteria.

So, it becomes important, as the Commission on National Prevention of Infant Mortality has pointed out, that eligibility varies tremendously in States, varying from 16 to 100 percent of the Federal poverty level, and has to be part of any national solution.

Another financial barrier to adequate health care for the Medicaid population is inadequate reimbursement for prenatal and child care under this program.

The increasing cost of liability insurance for those, particularly family doctors, who deliver both child care and prenatal care has increased the propensity or the likelihood for people to be faced with a situation of inadequate access to health care. Even among families above the poverty level, the devastating effect of not having adequate insurance when faced with a child who has a special problem or who is chronically ill brings special emphasis to that particular problem.

Mr. Chairman, I appreciate very much the opportunity to be here today to help focus the attention that you have so ably brought to this important national health issue, and I will be happy to answer any questions that you have, sir.

The CHAIRMAN. Thank you, Dr. Jones. We will have all of the witnesses testify before we ask questions.

[Dr. Jones' prepared statement appears in the Appendix.]

The CHAIRMAN. Ms. Rosoff, would you present yours?

STATEMENT OF MS. JEANNIE I. ROSOFF, PRESIDENT, THE ALAN GUTTMACHER INSTITUTE, WASHINGTON, DC

Ms. ROSOFF. To a considerable extent child health, at least in the early years, is shaped by events before birth, whether the pregnancy was planned, whether it was planned to arrive at the right time for the right couple in the right circumstances, and whether the mother received adequate care during pregnancy.

To some extent, the achievement of both prenatal care and access to family planning should be the concern of this committee. In the early 1970s, in fact, the committee was very involved and concerned with access to family planning services. This has diminished over time, but we hope that that interest can be rekindled, if only, as Dr. Jones mentioned, because of our concern with the incidence of teenage pregnancy.

But my testimony here today will address the question of prenatal care and the financial aspect of prenatal care.

For many, many years there were reports by either providers or women that obviously money made a difference, and some people just did not have the money to get access to care.

We conducted a very large study, in which we surveyed insurance companies, Blue Cross/Blue Shield plans, Medicaid Commissioners, Medicaid agencies, and all of the data which government has gathered which bears on this subject.

We found, first, about the characteristics of the people who are not covered. Twenty-five percent of all women of childbearing age are not covered by any kind of insurance—public, private, paid for with their own funds, or any other form. This is a very, very large number, clearly.

Still, half of the pregnancies are unintended at the time, so that clearly these women did not have a chance to save money to pay for the cost of medical care; and, since most of these young women are under 25—most first babies are born to women under 25—the income of these families is small. I mean, they are starting in jobs, they move from job to job, sometimes they work part-time.

The average income is less than $20,000 for an average couple in their twenties. Yet, the cost of having a baby under the best circumstances, on the average, is $4300. Now, that is if all goes well, and probably if you are living in a small or medium-size city. If you live in an urban area, it is going to be a great deal more. As we have heard, if something doesn't go well—and that does happen—then the cost can be absolutely enormous.

Now, most women have some form of private insurance, but not all policies cover pregnancy as a condition. This is because there are loopholes in the Federal Pregnancy Discrimination Act, and also because many women who buy private insurance are not covered for maternity care.

In 1985 there were over 300,000 women who had insurance that they had purchased with their own funds and did not have insurance for maternity care.

Also, many policies have waiting periods. Well, that may be fine for some conditions, but when you are pregnant and the months are passing, waiting periods will not be very helpful. Many policies exclude pre-existing conditions. That also works against the coverage of pregnant women. And many policies do not cover all needed services.

Public programs pay for about 20 percent of all births, and Medicaid alone accounts for about 17 percent of that. But again, the big difference is between the States. This has been noted before. Some States are a great deal more generous than others. Some States cover certain services and not others. Some programs like Maternal and Child Health, which supplement these efforts, are also very uneven.

The result of all of this is that, by the time a woman gives birth, there are still 15 percent of all women who have no insurance who are not covered by anything at all for the cost of the delivery. This means that sometime during the course of the pregnancy, some women manage to qualify for Medicaid.

But as we have heard before from Senator Chiles, the procedures for getting on Medicaid are so cumbersome that, yes, they may qualify for Medicaid, but just in time to go deliver at the hospital, and usually under emergency conditions.

The result of all of this is, not only do the women not get the care they need, but the providers are left with huge debts. I mean, it is startling to see that almost a third of all unpaid hospital bills in this country are related to maternity care. Twenty-seven percent. Twenty-seven percent of all unpaid hospital bills are related to maternity care.

This is not because parents who have their babies don't try to pay their bills, but that the bills are so exorbitant, and because, as I have said, they tend to be young and with entry-level jobs, and they just can't pay for this.

The CHAIRMAN. Ms. Rosoff, I am afraid I will have to ask you to summarize your comments, as required.

Ms. ROSOFF. Okay. Let me just touch upon the recommendations:

We published a very large report called "Blessed Events and the Bottom Line" in which we made a number of very elaborate recommendations about how to alter the Medicaid structure and the Medicaid-eligibility qualifications to take care of these problems. The list is long, and I think if we in fact adopted all of these measures one-by-one, and each State cooperated, that perhaps we would have the problem licked.

But as has been mentioned before by Senator Durenberger and Senator Chiles, I think there may be more useful and important ways to go at this problem and really to look at it as a form of entitlement for all women and children regardless of their income or ability to pay.

Thank you, Mr.Chairman.

The CHAIRMAN. Thank you very much.

[Ms. Rosoff's prepared statement appears in the Appendix.]

The CHAIRMAN. Dr. Perrin?

STATEMENT OF JAMES M. PERRIN, M.D., DIRECTOR, AMBULATORY CARE PROGRAM AND GENERAL PEDIATRICS, CHILDREN'S SERVICE, MASSACHUSETTS GENERAL HOSPITAL, TESTIFYING ON BEHALF OF THE AMERICAN ACADEMY OF PEDIATRICS, BOSTON, MA

Dr. PERRIN. Thank you, Mr. Chairman.

I am James Perrin, a pediatrician on the staff of Massachusetts General Hospital in Boston. I practice general pediatrics, with a special emphasis on working with families whose children have long-term health conditions, and today I am testifying on behalf of the American Academy of Pediatrics.

At the outset I want to commend you, Mr. Chairman, and your committee, for tireless advocacy on behalf of children. Despite the specter of punishing deficits, through your leadership this committee has successfully fashioned significant improvements in Medicaid for mothers and children each year, at least since 1983.

Senator, the problems of healthy children and children with long-term chronic health conditions are not fully separable. Although chronically ill children may have special needs, they face many of the same problems of access and benefits, and public solutions require coordinated efforts, among public and private efforts and between public programs, especially Medicaid and Title V.

Many children still lack access to adequate health services in this Nation. In 1985, Medicaid reached only 46 percent of the poor and near-poor children in America, down from 65 percent a decade before.

Access is even more difficult for children with long-term illnesses. Among poor children, those with a chronic illness are about twice as likely to lack Medicaid coverage as are those children who are apparently healthy.

Further, as we all know, there is great State-by-State variation in eligibility and in benefits for Medicaid.

Second, the EPSDT program, although conceptually an excellent idea offering broad benefits and emphasizing early detection and treatment of health conditions, nevertheless has never met its promise, succeeding in getting services to only about one-fifth of the eligible child population.

Third, although Medicaid has generally supported preventive and health maintenance services, the large majority of American children who receive their care via the private insurance sector typically lack coverage for this most cost-efficient part of the health care, preventive services.

I am pleased to say that the recently-passed Universal Access Bill in the Commonwealth of Massachusetts mandates coverage of preventive services for children when this bill is fully implemented at the beginning of the next decade.

Let me turn very briefly to the related problems of chronically ill children. Much of what I will share comes from work we did at Vanderbilt and the Vanderbilt Study of Chronically Ill Children and their Families.

Senator, with much gratitude for your own personal efforts on behalf of children, I would like to leave with you a copy of the summary and recommendations of that study.

The CHAIRMAN. Thank you very much, Doctor.

[The summary appears in the Appendix.]

Dr. PERRIN. Children with long-term illnesses live out their lives in the twilight of public understanding. They are often referred to by the names of their diseases —"diabetics, cystics, hemophiliacs"—rather than by their real names, Tom and Mary and Susan and Margaret.

Ten to 15 percent of children have some kind of long-term illness. Two percent of children in America have severe long-term illnesses, and the most important fact to share with you is that——

The CHAIRMAN. Slow down just a little. I want to be sure I hear all of that. Back up. Back up a paragraph and start over.

(Laughter)

Dr. PERRIN. Ten to 15 percent of children in America have some kind of long-term health condition. Of that number, the total number of children in America with severe physiologically, problematic health conditions is about 2 percent. And that number is a fairly stable number.

The important message to share with you, Senator, is that 80 percent of those children with severe long-term illnesses today survive to become young adults; they no longer die. Twenty-five years ago, most children with severe illnesses died.

Our task now is how to help them become effective, functioning members of our young adult society, which they can be.

These children, as well, often lack basic coverage. We know, unfortunately, that they too lack access to typical preventive services. It is surprising that children with long-term illnesses actually are even more likely to lack basic immunizations and basic health screening, compared to other able-bodied children in America.

What, then, are some solutions that we might consider to some of the problems we see?

Many of us have appeared before this committee or similar forums in the past. On each occasion, we have generally reviewed what is known about the statistics and have presented a series of legislative recommendations. Indeed, we probably could have just resurrected most of the previous testimony today and said, once again, that children in America lack basic services and need some improvement.

Our carefully-written statements, however, are good rhetoric and, our good intentions aside, it is time to realize that this approach is not working. After a decade of incrementalism, the state of our children's health has not improved commensurate with our resources, and our children's health care system is as fragmented as ever.

We call now for a universal access program with comprehensive benefits, including preventive care, for children to age 21 and for pregnant women in America. It should be available to all pregnant women and to all children in this Nation.

This program could be developed through a major expansion of Medicaid, including mandated national standards of eligibility and of benefits, with a package perhaps similar to that currently offered through the EPSDT program.

At your last hearing, Senator, Governor Mabus, for the National Governors Association, testified about how important it was from his viewpoint to have to have mandated benefits under Medicaid rather than optional, and we would support that as well.

The CHAIRMAN. Doctor, you will have to summarize, because we have limited time.

Dr. PERRIN. I am just about to be there, sir.

Second, and finally, in synchrony with the development of a universal access program, we would call for a revitalization of the Title V Program, for expanded responsibilities for assessing the health of mothers and children, for the development of special programs such as comprehensive community-based services for children with special health needs, such as was recently called for by the Surgeon General, for the support and needed special services that will not come from insurance mechanisms, and for the development of effective methods of coordinating care for families with children with special health needs.

We have a more complete testimony that we will provide for the written record, Senator.

Thank you very much.

The CHAIRMAN. Dr. Perrin, we will take it in its entirety.

[Dr. Perrin's prepared statement appears in the Appendix.]

The CHAIRMAN. I well know of the leadership that you have exercised in work on critically ill children and your classification of those illnesses. It has been very helpful to us in developing some of the numbers that we need for our programs.

Senator Chafee, would you care to make a comment?

OPENING STATEMENT OF HON. JOHN H. CHAFEE, A U.S SENATOR FROM RHODE ISLAND

Senator CHAFEE. Yes, Mr. Chairman.

Mr. Chairman, if I might, I would just like to make an opening statement, very briefly, right now in connection with this very important hearing, that we congratulate you for holding.

We have been moving slowly forward in our fight to provide health care services to low income children and to pregnant women, and in each Reconciliation Bill we have covered a few more people. Most of the members of this committee have joined in that effort. But it is clear that we are not moving fast enough.

The number of children without any form of coverage continues to climb. Between 1982 and 1985 the number grew by 16 percent. I think we have got to extend health care coverage to all individuals, especially children and pregnant women. I also believe we must restructure our system to represent a "well care system" rather than a "sick care philosophy." Every child, it seems to me, ought to be given every chance to be born healthy.

That is the compassion side of it, which we all believe in strongly here. If you just look at the economic side of it, the average cost of long-term care for a disabled child in an institution is an average of $40,000 a year, which adds up to a million dollars in a lifetime; and yet, with good prenatal care that would cost under a thousand dollars.

So from every point of view, Mr. Chairman, this effort makes sense, and I hope we can get on with it and take care of low income children.

All children, as you say, Dr. Perrin, up to the age of 21 should be taken care of, and certainly low income pregnant women should receive the best possible care this Nation can provide.

Thank you, Mr. Chairman.

Senator ROTH. Thank you, Senator Chafee.

Until the Chairman returns, let me raise a number of questions. We have 50 different States, each with a different Medicaid program. Some could give us some pointers as to how to move effectively. Which State programs for infants and pregnant women have been most successful, and are worthy of study, particularly from the standpoint of care but also from the standpoint of cost effectiveness?

Do any of you care to answer? Ms. Rosoff?

Ms. ROSOFF. There are two developments which I think have been very encouraging. One is that, traditionally, the States which had the lowest eligibility standards for Medicaid were the Southern States, and I think in the last few years they have made great strides in terms of expanding their services to low income women, both for pregnancy care but also for young children.

But I think it is instructive that two States which have made a major effort in this area—Massachusetts and California—have really found it necessary to not only raise their eligibility standards greatly but to some degree divorce the program for pregnant women and children from the traditional Medicaid program. I don't know all of the details of this, but I think it is instructive that they found it very difficult to work with a system which has developed over a period of almost 30 years and is now so tangled in bureaucratic red tape that it is very difficult to make it work.

Senator ROTH. Do you other gentlemen have any comment?

Dr. Jones?

Dr. JONES. I would say, Senator Roth, that it seems to me that you have sort of gone right to the heart of the matter. I think all of us here would agree that the eligibility, difference, and unevenness across the country is one of the major problems. It has to be addressed, apparently, in some legislative way.

Dr. PERRIN. I would just add, very briefly, Senator Roth, that 31 percent of Medicaid mothers really obtained adequate prenatal coverage compared to about 80 percent of non-Medicaid mothers in this country. So the problem is not simply, "How do we pay the bills?" It is also, "How do we use this resource effectively?"—probably tying it into Title V, most likely, to be a way of organizing services as well as paying for them at the community level, and trying to support high quality prenatal services for women that way?

Senator ROTH. Are there any particular state programs you would recommend we study?

Dr. PERRIN. Well, I think Massachusetts is in fact a State that is worth looking at; although, I would not say I would look at the City of Boston, where we are still doing dismally with respects to adequacy of birthweight, especially among Black populations.

Senator ROTH. The Chairman has returned.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you.

One of the problems is the complexity of improving access to primary health services for children. The complexity of it has been underlined in some of these comments.

What can we do in the way of getting more doctors to take Medicaid patients, other than just raising the level of reimbursement? Are there other things we can do? Other than just that, in this time of budget crisis?

Dr. PERRIN. I think there are some other things to do, and I think it does mean what my colleague to the right just said a moment ago, that trying to look at ways of not necessarily breaking children's and mothers' Medicaid from other Medicaid resources, but at least developing a focus on mothers and children within the Medicaid program. I think that will make a great step forward.

The mechanisms for that at the community level are in fact to realize that it is not simply having obstetricians and pediatricians see these families; it is also helping them to get the other kinds of needed resources around that are going to get them adequate nutrition, adequate transportation, adequate access to emergency services, and so forth.

Yesterday, actually, in my office, I saw the oldest first pregnancy I have seen probably in a year, Senator. She was 21 years old. I usually see young women who are more like 15 or 16 years old with their first pregnancies. This lady at least has some resources and knows how to find her way to some services. However, she does not have terribly good nutrition.

It is really trying to find out how we can build the breadth of services and not just how to reimburse me as a pediatrician or others as an obstetrician. That is important, but it is much more important to build the community base of services for women, so that they can make easy access to needed services.

Ms. ROSOFF. Since I am not a doctor, I would like to plead for the doctors, because I think our studies showed that on the average the physician reimbursement for prenatal care is about three-fourths of what normally the physician would get.

But if you look at the differences between the States, it makes absolutely no rhyme or reason. There are States that are paying their doctors very well, and States which are equally wealthy that do not pay their doctors at all.

The doctors'—particularly the obstetricians' and the gynecologists'—costs for malpractice insurance has gone up. And you know, the milk of human kindness I think only goes so far. I think it is not fair to ask physicians to assume the burden that the taxpayers have the responsibility to assume.

I also would say—and Mr. Chairman, you appeared startled when I mentioned the amount of unpaid debt which is due to hospitals because of maternity care—again, I think hospitals have to almost defend themselves against these costs. You know, this results in dumping and sending patients away, and asking for preadmission deposits which a lot of patients can't meet.

So, money is not everything, but I think it does count, and I think we tend to assume that somehow this charity care should be given by someone, but not us.

The CHAIRMAN. I was quoting a situation in a major city earlier, about where they would have this young woman go one place, and she would spend a half a day away from her work, and then when she moved from prenatal health care to delivery, she went to another hospital and went through the whole process again. At least in the first instance, she would give up. It is as though they were trying to stop her.

I have a son who is on the National Board of Directors of the March of Dimes who got himself involved in that program and straightening it out, and tying the computers together to save the second limitation in time.

But that is just one of the many things you are talking about that you run into at the local level, and making the service very difficult to be provided.

Senator Danforth?

OPENING STATEMENT OF HON. JOHN C. DANFORTH, A U.S. SENATOR FROM MISSOURI

Senator DANFORTH. Mr. Chairman, thank you very much.

Is part of the problem lack of information on the part of pregnant women and mothers of young children, that it would be a fairly simple matter for them to follow the advisable course in their pregnancy and in the early months of life of their child, but they just don't do it?

Dr. JONES. I think it is a two-edged problem, Senator. I think one is certainly a lack of information, as you pointed out. All too often these are teenage mothers who have had no access to much of this information themselves.

The other problem, as has been mentioned several times today already, is access. They simply don't have anyplace to go with adequate health professionals who are knowledgeable about these matters to turn to.

Senator DANFORTH. Teenage pregnancy is a good part of the problem, is that right?

Dr. JONES. It is the major problem.

Senator DANFORTH. A major problem. And is a substantial portion of the low birthweight babies attributed to teenage pregnancy? The answer is Yes?

Dr. JONES. Yes, sir.

Dr. PERRIN. Yes, sir.

Senator DANFORTH. And are these often young kids who would be from disadvantaged backgrounds?

Dr. JONES. Frequently so; yes, sir.

Senator DANFORTH. Frequently so?

Dr. JONES. More frequently so. Yes, sir.

Senator DANFORTH. And isn't it true that there are some things that pregnant women can do that would increase the likelihood that their babies would go to full term?

Dr. JONES. Yes, sir.

Senator DANFORTH. What kinds of things would be advisable for say a 15 year old girl, if she wanted to deliver a healthy baby? What would you advise her if she came in to see you?

Dr. JONES. Senator Danforth, I don't know if you were here when Senator Chiles spoke, but he himself mentioned several of those things, nutrition being one of the major ones, appropriate diet, which is good for the mother and the baby during that time, avoidance of smoking, avoidance of alcohol—the Alcohol Fetal Syndrome, which is now well known—and so forth. Simply, that information either isn't available to many of those young pregnant women, or they choose to ignore it because of the particular social situation they find themselves in.

Senator DANFORTH. Could you quantify the effect of lack of knowledge on premature birth? Is this speculation, or have there been some studies that demonstrate the relationship?

Ms. ROSOFF. I think we know. We used to think that, if you had a baby in your teens, you were at a higher risk. And we have found that in fact you are not biologically at higher risk; you are at higher risk because you are unmarried, you didn't want, usually, to have that baby, you are living in very poor circumstances. But if you get very good care, you will do just fine.

The question is that that is very expensive care, and it means a lot more than the traditional sitting down with the doctor; clearly, it means a lot of social supports which are usually not available to these young women.

So it is not purely a medical question in a narrow sense; it is simply that if you are unmarried, and you don't have social support, then if you are very young and don't have social support you have a very hard time, and you are not likely to do well physically—not because you are unable to do well physically but just because you don't have the kind of support you need.

Senator DANFORTH. Let us take a 16 year old girl, unmarried. She finds that she is pregnant. She wants to deliver the baby. And she is highly motivated. Typically, are there resources in a community to take care of that girl? If she says, "I want to deliver a healthy baby," can she do so?

Ms. ROSOFF. If she is lucky.

Senator DANFORTH. If she is lucky? Well, if she were highly motivated she could decide to follow proper nutrition, she could decide to not smoke or drink, right?

Ms. ROSOFF. Yes.

Dr. JONES. Certainly.

Senator DANFORTH. What else would she do? She would want to be in contact with a physician.

Dr. JONES. Yes, and to have her weight monitored, to have her blood pressure monitored, the growth of the infant to be monitored.

Senator DANFORTH. Is that generally available? Could she get that pretty easily? Or is that difficult?

Dr. JONES. I think that is one of the problems, Senator, that it is unevenly available. It is not as available in inner cities, in my experience, and it is not as available in some rural areas as it might be, because of the problem that the Chairman mentioned earlier. There is a lack of primary physicians, both primary pediatricians and primary family doctors, in that area.

That is my bias, to answer your question, Senator.

Senator DANFORTH. Here in the District of Columbia there was an advertising campaign on television. I don't know if that is still going or not, but some time ago there was an advertising campaign on TV to urge women to consult doctors and I don't know what else, give up smoking or whatever. Are those campaigns, pubic outreach advertising-type campaigns, useful, or not?

Ms. ROSOFF. I think you will know shortly, because the Institute of Medicine is looking at this very question of how important is outreach. Obviously, outreach assumes that you have to have enough facilities to take care of people.

You know, it is am old debate: There is no sense testing people for various diseases if you can't treat them. You have to have a balance of both, it seems to me, both to serve the people and the outreach as well. But I would imagine the answers to that question will be known very shortly.

Senator DANFORTH. I spent some time with health care professionals in St. Louis, people who ran a major clinic in St. Louis. That is just one city, but they believed that it would be enormously important, and in fact they have undertaken an outreach campaign of their own.

I suppose they would always say, "Well, you know we could always stand more facilities," and so on, but they really believed that it was terribly important to try to get the information to the pregnant women as to what they should do, having found out that they were pregnant.

I am curious about whether this is something that we should somehow encourage. You say there is a study that is going on now. Maybe it is premature to make a decision on it.

Ms. ROSOFF. I think one of the questions, it seems to me, in the expansion of Medicaid benefits for pregnant women is that it will be difficult to do State by State. But it certainly will not happen if the States don't make a major effort to inform women that in fact they are eligible.

If the States, because Medicaid has been linked to welfare, have tended to try to keep as many people as possible away from registering, this is a campaign in which you want to go the other way, and you want to let it be known far and wide that in fact, if you are pregnant with a certain income, you are eligible, and you should come and get it.

If the States just pass a nice statement and just rest on their laurels, then I think women will not even know that they are eligible, and they will not know how to proceed.

Also, as Senator Chiles mentioned, if you have a 40-page long application which makes IRS returns seem very simple in comparison, I think if people don't come or don't make progress with the system it is not surprising.

Senator DANFORTH. Is the paperwork problem our fault?

Ms. ROSOFF. Do you mean Congress's fault?

Senator DANFORTH. Government's fault?

Ms. ROSOFF. Yes. I think there is so much fear that somehow somebody is going to get a benefit that they are not entitled to, that the bureaucracies try to defend themselves from this. So the net result, I think, may be the opposite of what we intended.

Dr. PERRIN. Senator?

Senator DANFORTH. Yes.

Dr. PERRIN. I think the issue of outreach is terribly important. It is more than simply advertising and the knowledge issue, it is also partly getting the services where people live and not centralizing them so far that it is a tremendous barrier for women to come into some central place to get that large amount of services available.

The second piece, and I think we have said it in a variety of ways, is that you are thinking again about that 15 year old young lady who is pregnant, who does want to bear a child at term. To simply say, "Well, we will figure out a way to get you into an obstetrician's office on a regular basis," is not sufficient. It may be necessary, but that young lady needs a good deal more service than someone who is at a much lower risk of having a preterm infant. We need to figure out mechanisms for doing that, as well.

Senator DANFORTH. Thank you very much.

The CHAIRMAN. Senator Chafee, have you had a chance to speak?

Senator CHAFEE. Mr. Chairman, I just want to ask a couple of questions.

I have followed this rather closely at home, and in my State, particularly in the City of Providence, they are making a big effort in the schools, through the school nurse and the school doctor, who is not there permanently but comes there on a regular basis. They have a tremendous effort that seems to be quite successful to catch the pregnancies that are in the school.

Now, as far as those who aren't in the schools, we have had considerable success with the health clinics, the federally supported health clinics, that are scattered around in the urban areas.

I must say that I am not quite sure about the funding for the physicians in those clinics. I seem to get conflicting stories about what the inducement is for a physician to come and serve in those inner city clinics.

Mr. Chairman, I will say this: I think it would be helpful, and I am not sure it is even under our jurisdiction, to find out what are the inducements for physicians to come and serve in these inner city health clinics. There is various excusing of loans that have been granted to that physician when he was going through medical school, if he or she will serve x-years in the inner city health clinic.

Do you know much about that, anybody here?

Dr. JONES. Well, Senator Chafee, lots of those strategies have certainly been employed. I think altruism on the part of the physician certainly plays a large part.

The truth of the matter is, though, there just aren't enough people who are compelled by human compassion to do those, as was mentioned earlier. I think I would certainly agree with you that investigating the motives and assuring access by having the right number of people there is an important part of it.

It has been suggested that perhaps physicians in that certain sense might be forgiven their income tax for a year as a way of motivating them to come out there. A noted economist from your State recommended that perhaps a 30 percent increase in the MEI to physicians practicing under those circumstances might be an appropriate inducement. I think I agree with you, sir, that that is part of looking at the problem of access to this very important problem. We have to get the right kind of practitioners in the right places.

Senator CHAFEE. I missed the correct name of these; it is Community Health Centers.

Mr. Chairman, I was just asking the question about the method. I think part of this problem revolves around the accessibility to physicians. In the Community Health Centers I have looked at at home, they have had some turnover in physicians and some problems in getting physicians. I am just not sure what the inducements are for the physicians to come there. I suppose that is not under our jurisdiction, is it?

The CHAIRMAN. Well, it comes under our jurisdiction to the extent that we influence it, I suppose, through some of the things such as reimbursement.

But there are other problems, and many. That is what we had discussed I think a little before you arrived.

Senator CHAFEE. There are certain inducements in forgiveness of loans, and so forth, that I am not totally familiar with. But in any event, the accessibility of the physician care obviously is a key component in this trying to keep these low income pregnant women healthy.

Dr. PERRIN. Mr. Chafee, I can't speak for obstetricians in this area, but the division that I run includes about 15 general pediatricians, about two-thirds of whom in fact work primarily in neighborhood health centers that relate to the Massachusetts General Hospital, and the issues are not financial. I mean, most of those folks make perfectly adequate take-home, living wages.

They are not concerned really a great deal about their dollars; they are much more concerned about the kinds of conditions they are working in and the kinds of ability they have to really make some change in the health status of the young people that they are concerned about and working with. I think that is the issue that makes it attractive for them to be there.

If they can see some progress on the issue of adolescent pregnancy, if they can see some progress in issues of adolescent substance abuse as a result of their activity there, if they can see some things that help young people grow up to be more effective members of our society, that is what makes them want to stay there, frankly. It is that kind of a return on investment that I think is important. That is very hard to put in dollar terms.

The CHAIRMAN. Thank you.

Senator Baucus?

OPENING STATEMENT OF HON. MAX BAUCUS, A U.S. SENATOR FROM MONTANA

Senator BAUCUS. Thank you, Mr. Chairman.

First I want to commend all of you for your efforts and work in this area. The importance of preventive care is becoming more evident to more members of Congress. Not only do these efforts help to ensure that we have healthy children, but they lower the overall cost of health care in the long run.

I would like to ask the panelists, in particular Dr. Jones, a question regarding page 3 in the testimony.

On page 3, in the final paragraph, you are talking about financial barriers to adequate health care: "For example, according to the National Commission to Prevent Infant Mortality, Medicaid reimbursement for maternity care is far below the prevailing rates for these services in some areas, and the increasing cost of liability insurance adds to an already difficult situation." I am wondering what we should do about that.

You go on, on the next page, and talk about Senator Bradley's bill, which I think is a good bill. As I understand his legislation, he directs States to assess whether their reimbursement rates are reasonable. Then, if the States think it is unreasonable, the States themselves would take appropriate action.

But some States are pretty hard-pressed financially to up their Medicaid reimbursement rates. The Federal budget is pretty hard-pressed, too. I am wondering if you have some other ideas.

Some have suggested, maybe on a demonstration basis, a matching program—that is, if States increase their reimbursement Medicaid rates, Uncle Sam will match it in some way.

Do any of you have any thoughts on how we can encourage some States to have higher Medicaid reimbursement rates, so as to help assure that those women have better health care for their kids and to lower the cost of liability insurance?

Dr. JONES. Senator, I would comment on that in maybe a more slightly tangential way than you might have ended up asking the question.

I think that the Academy of Family Physicians is interested, as you are, in making sure that all Americans have access to high quality care.

I think, to the extent that reimbursement for preventive care has not been rewarded very highly under our present system, we have spent bigger bucks on curative medicine than we have on medicine that has been preventive. I think during the current opportunity of reforming and turning around physician payment schedules, which you will have the opportunity to do, that is a problem that has to be addressed as part of the access to health care, particularly for the population group we have been discussing this morning.

Specifically how to help States get more money to fund those programs, you are much more of an expert at that than I would be, sir.

Senator BAUCUS. You are saying one way to approach it is with the fee schedules for physicians?

Dr. JONES. If we would reward physicians and other health care providers at least equal incentive to practice preventive medicine as we have to practice curative medicine, or as we would say in North Carolina "to close the barn door before the horse gets out," it seems to me that you have opportunity to change the focus of emphasis in health care delivery by doing that.

Senator BAUCUS. Do you know whether this relative-value study addresses that problem?

Dr. JONES. Yes, sir, it does. I have been involved with that since its inception, and it does. Yes, sir.

Senator BAUCUS. Thank you very much.

The CHAIRMAN. Thank you.

Thank you very much for your presentations.

Our next panel will be Ms. Barbara Matula, who is the Director of North Carolina Division of Medical Assistance; Ms. Sara Rosenbaum, Director of the Health Division, Children's Defense Fund; Dr. Archie Golden, Medical Director of The Chesapeake Health Plan; and Ms. Helene Botsonis, for the Texas State Public Affairs.

Ms. Matula, would you present your testimony, please? And if you would, limit your comments to five minutes. I am afraid we are going to get a vote over on the floor of the Senate, plus we have a caucus that we have to attend. So, if you would proceed, please.

STATEMENT OF MS. BARBARA MATULA, DIRECTOR, NORTH CAROLINA DIVISION OF MEDICAL ASSISTANCE, TESTIFYING ON BEHALF OF THE STATE MEDICAID DIRECTORS ASSOCIATION OF THE AMERICAN PUBLIC WELFARE ASSOCIATION, RALEIGH, NC

Ms. MATULA. Senator, I am going to let you folks read the testimony at your leisure, and I am going to very briefly in my remarks try to answer some of the questions that were asked of the last panel, instead.

I have been State Medicaid Director in North Carolina for about 10 years. I have chaired the National Medicaid Directors Association for four years, which means I have gotten a close-up look at a lot of different programs. I have worked with APWA's access to a health care task force which is concerned about the uninsured and their access to health care across this Nation, and I have had the privilege of serving on the National Commission to Prevent Infant Mortality. So I have kind of been in lofty heights and down in the trenches, all at the same time.

I assure you, at times I feel like an apologist for Medicaid, and that is because I understand its weaknesses. But at the same time, I appreciate Medicaid a great deal for the potential that is there. I flinch when I hear what "those terrible bureaucrats" are doing, because at the same time many of us at the State level are doing it with a gun pointed to our heads, because we are told about cost-containment, and third-party liability, and prior approval, and so on and so on, all of which adds to the paperwork burden for physicians and hospitals and other providers.

The States that are the poorest enroll the fewest number of people and have the greatest burden of uncompensated care in those States. They are struggling not only to make strides in preventing infant mortality, which is highest in the poorest States, but also to deal with the heavy burdens of long-term care for the elderly and the disabled, which also fall to Medicaid. So it is a juggling act that we perform.

For Medicare eligibility, you need only turn 65; but for Medicaid eligibility you have to walk through the eye of the needle, and you have to do it over and over—not just one time, but many times.

I think we have jumped on the initiatives that you have allowed us in expanding eligibility for more pregnant women and infants, and I think that what States have done in both outreach efforts, in case management, in expanding services, in working with their fellow public health agencies, in ensuring that nutritional needs are met—I think the proof will be in the pudding, and we will see it soon, that we can do a good job when we can unlink Medicaid eligibility from cash assistance rules.

We are not finished there. We have a few, polite, "ways to go" to make that delinking complete.

I will give you a perfect example: The American public does not want welfare assistance to go to families where there are not two parents supporting that child, unless that parent that is absent contributes to the support of that child. That is The American Way, and that is wonderful. But when a young girl finds she is pregnant and applies for assistance in any State in this Union, she is required to identify the father of that unborn child before she can qualify for Medicaid. I don't think that is appropriate. I think there is time enough to pursue the father of that child and support for that child after the baby is born, and not to use that as another barrier to receiving medical care.

We have, in the Medicaid program, I think a model for both private insurance and others in the EPSDT program—which sounds like an immunization or a disease but really is a model program for screening, diagnosis, and treatment of health care problems, not just for infants and children but for teens.

While States are mandated to provide EPSDT, we do not automatically enroll the mothers and their children for EPSDT. We have to ask them if they want it. They have to actively consent to it. At the point of trauma, of eligibility intake, we are telling mothers, "If you don't want this, you don't have to take it," or something to that effect.

The CHAIRMAN. Ms. Matula, I will have to ask you to summarize your testimony today.

Ms. MATULA. Okay, I shall.

I think there are good recommendations States could make for further breaking the links to cash-assistance rules, for tying together services that are already paid for and provided with public funds, and for bringing healthier babies, healthier teens—please don't leave out the teens—through the Medicaid program and improve provider participation at the same time.

Thank you.

[Statement of Barbara Matula appears in the Appendix.]

The CHAIRMAN. Thank you.

Ms. Botsonis, we are pleased to have you. You will be testifying representing the March of Dimes. I attended your dinner last night here. Incidentally, I think it was a big success.

STATEMENT OF MS. HELENE BOTSONIS, R.N., TEXAS STATE PUBLIC AFFAIRS VOLUNTEER, AND MEMBER, MARCH OF DIMES NATIONAL COUNCIL OF VOLUNTEERS, TESTIFYING ON BEHALF OF THE MARCH OF DIMES, AMARILLO, TX

Ms. BOTSONIS. Thank you very much, Senator Bentsen. We appreciate your and Mrs. Bentsen's support in our volunteer efforts.

I am here as a March of Dimes National Council of Volunteers member. I am also here as the Texas State Council Volunteer for Public Affairs in our State, and I am also here as a Registered Nurse, with years of public health experience in working for a community action agency in providing care to low income families in the Texas Panhandle. I have had a strong personal and professional interest in maternal and child health for a number of years.

This year the March of Dimes celebrates its fiftieth anniversary and its 50 years of advocacy to improve child health in America. We are very pleased to be asked to participate in these hearings today. We want you to know that 30 of those 50 years have been dedicated to the prevention of birth defects.

You have in your hands a lengthy statement which I will attempt to summarize, and I would also like to respond to any questions.

Mr. Chairman and members of this committee, we commend your commitment to the health and welfare of mothers and children, and we are encouraged by the work of this committee and by these hearings as well.

If the United States is to reduce its tragically high rates of infant death and illness, we must improve our national maternal and child health system now. There are ways that this can be accomplished.

The first step in improving our national maternal and child health care system is to implement strategies that we know have been effective.

Years of study have shown us that early prenatal care, allowing for a timely diagnosis of potential or actual problems in pregnancy, can result in a better outcome of that pregnancy, and we heard several comments to that effect this morning.

The Medicaid eligibility level for pregnant women and infants must be raised in all States to the Federal poverty level. Lack of money is the foremost reason that uninsured women and Medicaid recipients delay care until the second or third trimester of their pregnancy. Often these women are the "walk-ins" that were referred to earlier, who come to the hospital in labor to deliver a baby, and they have had no prenatal care.

Right now, many women, many poor women, are not eligible for Medicaid, or they are unable to receive care because of non-financial barriers to care. Some of those non-financial barriers include multiple and confusing eligibility requirements for benefits, which was spoken to so well a little earlier; inadequate provider reimbursement; maldistribution of providers.

We talked about physicians as providers, but we also need to look at standardizing reimbursement across this country for certified nurse-midwives and nurse practitioners who can deliver prenatal care to many of these women. Another non-financial barrier is the underutilization of these certified nurse-midwives and nurse practitioners.

We must improve coordination among existing programs to provide comprehensive services to pregnant women. Medicaid must be coordinated with the WIC program, (the Women, Infants and Children's supplemental food supplement program), the Community and Migrant Health Centers program; and the Maternal and Child Health Block.

We need to coordinate these programs to a single effort and single points of service so that pregnant women may gain access to labor and delivery coordination, as well.

We must strengthen the Maternal and Child Health Block Grant program. Improved accountability would allow the Federal Government to oversee this program. Allowing these funds to be diverted to other uses can negate the opportunity that Medicaid expansion provides for serving more poor women.

We are concerned that the Maternal and Child Health Block program does not have a "maintenance of effort" requirement, and that increases in federal funds are sometimes supplanting State funds.

We must assist families of infants incurring exorbitant medical bills. Average hospital bills for very low birthweight babies—those of 1500 grams, or approximately three and a half pounds—can run $50,000 per child. There are nearly 10,000 babies born every year in this country that require hospitalization care costing in excess of $50,000. Families of these babies are devastated by the enormity of these costs, not to mention, Senator Bentsen, as you said earlier, the emotional impact of occurrences like this.

The CHAIRMAN. I will have to ask you to summarize, as the time has expired.

Ms. BOTSONIS. Thank you.

Another step in improving our national maternal and child health care system is to test new strategies, such as studying and replicating innovative programs to increase the availability of care providers, and to develop innovative financing strategies, and to develop outreach programs and incentives for prenatal care through demonstration projects.

The third step is to continue to conduct research on the causes and prevention of infant mortality.

The United States must make improving child health a top priority. We heard children referred to as "our national treasures"—we must protect those treasures.

Thank you.

The CHAIRMAN. Thank you very much.

[The prepared statement of Helene Botsonis appears in the Appendix.]

Ms. Rosenbaum, you are here representing the Children's Defense Fund. We are very pleased to have you.

Again, I have a son who gets involved in that one. He works with it back in Texas.

STATEMENT OF MS. SARA ROSENBAUM, DIRECTOR, HEALTH DIVISION, CHILDREN'S DEFENSE FUND, WASHINGTON, DC

Ms. ROSENBAUM. Thank you, Mr. Chairman. And thank you for everything that this committee does for children.

I want to make three principal points today. The first is that this decade has witnessed the virtual demise of any employer-provided health insurance system for children.

Based on data that we are preparing for a book to be issued in the Fall, we found that over a five-year period, 1980 to 1985, the percentage of low income children with employer-provided insurance fell by 25 percent. For the youngest low income children it fell by 35 percent, from 18 percent to 12 percent. There is no longer a mainstream employer-provided health insurance system for poor children.

The second major point is that, despite notable strides in Medicaid improvements—and I want to second what Barbara Matula has said, that the State response to the Medicaid options that Congress has put forward have been remarkable—despite those notable improvements, in fact we are barely holding our own because of the vast increase in the number of poor children. That is going up almost as fast as the number of children with Medicaid.

The third and final point is that in thinking about remedies, I think it is very important that we begin to put children back together.

Over this decade, in part because we have wanted to try to keep incremental reforms going during a very, very difficult national policy period, we have thought about subpopulations of children. I think the time has come to think again in broad terms, to put children back into one piece. All children need eligibility for basic benefits.

In preparing our forthcoming book, I have had a chance to read through the original Medicare debates, and what is so striking about them is how similar they are to what we are all talking about today.

There are children who will need a great depth of benefits for high cost care; there are children who will need an equal depth of benefits for routine primary services.

It is important that Congress continue on the path that it has been pursuing in terms of its Medicaid reforms. It has made the program broader, more accessible.

The recent provisions in the Welfare Reform legislation to shore up the employer system are important.

Senator Chafee's Med-America Bill, with its new structure for premium-adjusted buy-in arrangements for near-poor families, along with the Bradley Maternity Bill that passed last year, which also provides for an income-adjusted premium buy-in system, are the kinds of reforms that interestingly were discussed 23 years ago in the Medicare debates.

That is the appropriate path, we think, to take at this point—basic, universal plan that acts as a primary payor for some children and is a secondary supplemental payor for other children, just as the elderly have evolved a system of Medicare and retiree benefits.

The final point is one that was raised by Senator Chafee and by yourself. That is the importance of thinking about the resources to deliver services, as well as the financing of those services.

As Senator Chafee pointed out, a number of resource delivery programs, and unfortunately the most important ones, such as the National Health Service Corps and the Community Health Centers Program, are not directly in the jurisdiction of this committee; although, as you yourself pointed out, your reimbursement approaches can have an enormous impact upon the viability of publicly financed providers working in underserved areas.

We also think that it is extremely important that as we think about the Title V Maternal and Child Health Block Grant, we keep mind not only the mission of that program in terms of helping children with high-cost medical needs, as Senator Chafee's reform package for disabled children last year dealt with. It is also important to remember that that program plays a major role in the development of primary care services, particularly for children. And in that area, the program has fallen down. It has simply not been as aggressive in furnishing basic health care services for low income children with normal medical needs as it has been in the development of services for high-cost children, and we urge that both sides of the program receive equal attention.

The CHAIRMAN. Thank you, Ms. Rosenbaum.

[The prepared statement of Sara Rosenbaum appears in the Appendix.]

Dr. Golden, if you would proceed, please.

STATEMENT OF ARCHIE S. GOLDEN, M.D., MEDICAL DIRECTOR, THE CHESAPEAKE HEALTH PLAN, TESTIFYING ON BEHALF OF THE CHILD WELFARE LEAGUE OF AMERICA, INC., BALTIMORE, MD

Dr. GOLDEN. Thank you, sir.

I am Archie Golden. I am a pediatrician and Medical Director of the Chesapeake Health Plan in Baltimore that provides comprehensive health services to many of the foster children in Baltimore, and my topic today is Health Care of Foster Children.

I speak on behalf of the Child Welfare League of America, which last year convened a group of experts to focus on problems inherent in the delivery of health services to children in foster care.

First, briefly I will discuss my own experiences, providing care to foster children in the past seven years.

They are placed in care because they are abused, neglected, or abandoned, and therefore are extremely vulnerable to having medical and psychological mental health problems.

In our practice, we have found that 29 percent of the children have visual and eye problems—that is almost a third. Over half have mental health problems, and most of those in the primary school years have learning disorders and educational problems. It is rare for me to see a good report card, and I, as a physician, ask to see report cards also.

Foster children have many chronic health problems such as asthma and hyperactivity, and our foster children are smaller in height than other children of the same age, sex, and socioeconomic status.

Our situation in Baltimore is somewhat unique in the United States in that the State of Maryland contracts with us, a Health Maintenance Organization, to be the primary site for health care for Baltimore children, and fund us on a monthly capitation basis to provide comprehensive care, including the EPSDT program and all necessary services.

Now, let us go nationwide for a moment and look at the picture. Here are some of the problems with foster children and their health and services:

Child welfare and health agencies have little or no communication or coordination.

In an overburdened child welfare system, health care is low priority.

There is no adequately organized health system for foster children, generally speaking.

Information on health care for foster children prior to their entry into the system is often not available.

Foster children are not routinely entitled to health care services under child welfare agency auspices, until the responsibility for their care has been formally assumed by the agency.

Maybe most important is the fact that State Medicaid programs currently provide only limited access to the health care services needed by foster children.

There are no agreed-upon standards of quality for the health care of foster children.

And the collection and management of health information about foster children is generally not an organized process.

Now, we feel that the following public policy initiatives can be put forth to improve the health care of foster children:

Medicaid should be an entitlement for all children in foster care as a payor of last resort.

There should be mandated uniform health benefit packages for children in foster care.

Building on the Medicaid and EPSDT programs, the Child Welfare League calls for stringent application of an expanded schedule of services, not only including EPSDT but including pre-placement, post-discharge care, and supervision.

Also, we believe there should be Federal oversight with regard to medical recordkeeping and health care quality assurance programs.

Through the efforts of the Child Welfare League of America, a bill has been introduced in the House of Representatives which certainly, if passed, will be a move in the right direction. H.R.2753, introduced by Representative Robert Matsui of California would require the case plan of every child in foster care to include a health care plan.

The Chairman. You will have to summarize, if you will, Doctor.

Dr. Golden. Yes.

We propose that the Senate consider a companion bill to H.R. 2753.

Thank you very much for the opportunity to discuss this issue with you.

The CHAIRMAN. Doctor, on that point of Medicaid, one of the things that I was involved in was assuring that children who were adopted out of a foster home could take their Medicaid with them. I think that was of some help on that point you were talking about. And then to help establish a data bank for adoption purposes, so they would know the availability of these children and all. That is trying to get some of that information you were talking about available.

Dr. GOLDEN. Good beginning.

[Dr. Golden's prepared testimony appears in the Appendix.]

The CHAIRMAN. One of the things we brought in, I guess it was last year, was the so-called "pre-emptive eligibility" process under Medicaid, making it easier for providers to serve pregnant women without going through all of the lengthy eligibility determination.

Of those States that have started it or tried it, do any of you have any knowledge of the results?

Ms. MATULA. Yes, sir. It is working well, but it has got one or two bugs we would like to have worked out, if possible.

What presumptive eligibility does is ensure that a provider will be paid for services rendered in the first 45 days of a woman's pregnancy. But that doesn't have to happen, and that doesn't always happen. For that to happen, he has to first be a qualified provider. If he happens to be a pharmacist or a laboratory, he will not fit under the federal description of "qualified," and we cannot reimburse him.

Second, the provider must submit the paperwork within five days, or he will not be paid for services after the fifth day.

The pregnant woman must formally apply for Medicaid by the fourteenth day, or she will not be eligible under this presumptive period for the remainder of the 45 days.

Our information systems which qualify people for services and payment cannot really adapt readily to these 5-day, 14-day, 45-day hurdles that we go through, and we would recommend that the presumptive eligibility period be for 45 days, and that it be for payment of bills for any provider who renders services who is enrolled in the Medicaid program.

The form is simplified, especially for those States who have eliminated the assets test, which was an option that you allowed us. Those States that would retain an assets test would still put the woman through a very lengthy eligibility process at another site, the social services office.

The CHAIRMAN. Thank you.

Ms. ROSENBAUM. I would like say to that we are now in the process of interviewing providers in the 16 States that have implemented the program to date. Those States can be found in a table in the testimony.

The points that Barbara raised are exactly correct, but I do want to stress that every provider has reported to us that the program did exactly what it was supposed to do.

The CHAIRMAN. Do you mean we have something that is working?

(Laughter)

Ms. ROSENBAUM. Yes.

It has found in every site hundreds of women who previously were not enrolled in the program, who were coming for medical care but had not yet made it through the Medicaid eligibility process. I think, on that point, it is important to realize that moving Medicaid out of a welfare office and into the location where people come to get medical care has been one of the best changes this Congress has made in the program.

The CHAIRMAN. Thank you.

Ms. Botsonis, you were talking about improving outreach and the follow up for pregnant women. How do you find that is working?

Ms. BOTSONIS. One of the things in terms of outreach, Senator Bentsen, that was brought up a little bit earlier was the question of whether or not public education campaigns, which are themselves a form of outreach, are working.

I can tell you that March of Dimes has the campaign of "Mommy, Don't" which is the anti-drug, anti-smoking, the prenatal care messages. And invariably, when those are shown in communities, our local offices get a number of telephone calls from women who want more information. So we know that that, in terms of outreach, is working.

The follow up of these babies through various grant programs—and the Foundation is funding one—to pursue these babies that are lost to follow-up has proven to be very cost-effective. Remediation of early-detected problems can be put into effect right away. And those programs are indeed working.

The CHAIRMAN. Thank you.

On our early-bird arrival rule, we will start with Senator Chafee.

Senator CHAFEE. Thank you, Mr. Chairman.

Ms. Matula, you advocated the separation of AFDC and Medicaid, and I think we all agree with that. That, of course, is what the Med-America proposal does. Are you familiar with that at all?

Ms. MATULA. Yes, I am.

Senator CHAFEE. Do you approve of it? Do you give it a boost?

Ms. MATULA. Yes.

Senator CHAFEE. Good.

You mentioned two proposals that I find attractive: One, to stop requiring pregnant women applying for Medicaid to name the father. The current practice is what? They have to name the father?

Ms. MATULA. It is administered irregularly across States. In our region, for example, we have been told that it can be waived, but only under unusual circumstances. I think that ought to be clarified and be made uniform for the country.

Senator CHAFEE. It seems to me that what we want to do is eliminate all disincentives that we can for those to use Medicaid when they are eligible for it.

There are two points that you made: One is not having to name the father; two, not requiring the recipients to ask for ESPDT. Do you have any other suggestions?

Ms. MATULA. There is one that is quite tricky for us to handle. It has to do with making Medicaid eligibility available to pregnant teens who live at home. A teen that lives at home and is pregnant is counted as part of her parents' household for income purposes.

That household may be near-poor but not need Medicaid, and in a way we are penalizing that pregnant teen by requiring her parents to support her, even though their own insurance policies would not for prenatal and delivery costs.

We would urge you to consider that a pregnant teen living at home not be forced to move out of the house in order to qualify for medical care. We think that that is not giving her the support she needs at home, if she brings that baby home with her, and that is an exception that you might consider pursuing.

Senator CHAFEE. Ms. Rosenbaum, from your experience, which is certainly broad, and the others on the panel, is there a danger of Medicaid being swamped with applications from pregnant teenagers or generally low-income pregnant women if we were far more casual than we are now as far as the restrictions concerning eligibility? Do we have to be careful to hold the dykes, that the whole system will be overwhelmed? Is that a clear and present danger the system faces?

Ms. ROSENBAUM. Well, as Barbara just said, she hopes so, and so do I, because the Medicaid system will catch up with those children at some point. It will either catch up with them when they are pregnant, or it will catch up with them after the baby is born, in the form of very high cost medical bills.

The best thing that could happen to Medicaid is that it be swamped by low-income pregnant women and by low-income children. Right now, the Medicaid penetration rate—that is, the rate at which eligible people actually get to enroll in the program—is a fraction of what it should be. At best, States manage to get about 50 percent of eligibles in, and that is when the program is humming along.

Senator CHAFEE. Is the reason that the other 50 percent don't come in, and we are talking the best States, is that they don't know about it, or it is so complicated that they can't face a 10-page form? Or the services are not accessible? What is the problem.

Ms. ROSENBAUM. Perhaps the best way to answer that is to walk you through applying for Medicaid in the District of Columbia, which I choose only because we spent a fair amount of time looking at it last year. We looked specifically at the application process in the Adams-Morgan area, which is a predominately Hispanic area of town.

As of now, there is still not a Spanish language Medicaid application. The people in the Adams-Morgan area have to——

Senator CHAFEE. By the way, how long is a Medicaid application?

Ms. ROSENBAUM. Well, in the District it runs between 25 and 30 pages, and that is about an average.

Senator CHAFEE. Oh, boy. Are you serious?

Ms. ROSENBAUM. Yes, I am serious. It is quite a lengthy process. And the Alan Guttmacher Institute study noted, I think, a number that ran as long as 40 pages. Hawaii's form runs almost 50 pages.

Senator CHAFEE. Hawaii?

Ms. ROSENBAUM. Hawaii. And that is because States have attempted over the years to try and collapse into one form all of the questions that need to be asked for all public benefit programs, for fear of missing an eligible person. That is a laudable goal. The problem is that we really need to start rethinking that approach, since what we are doing, going back to my example, people have to travel across town to pick up an application, for which they need an appointment—they can't just get an application; they need an appointment to get an application.

You then need to go back to the Interpretation Center in the Adams-Morgan area to have somebody interpret the application to you. You are then given a list of accompanying documents that you must bring in, along with the application. And one of the items on the District's list is letters from two friends who can vouch that you are a good person. Now, where that requirement came from, we are not sure.

Senator CHAFEE. Why do you have to be a good person to be eligible for Medicaid?

Ms. ROSENBAUM. We don't know.

Senator CHAFEE. I will tell you this, that that form is longer than the Top Secret security in the United States of America.

Ms. ROSENBAUM. I am not surprised.

Senator CHAFEE. The form for Medicaid eligibility is longer than the Top Secret security clearance application, and probably requires far more detailed information.

Ms. ROSENBAUM. We estimated that it could take a pregnant women basically through her pregnancy to complete and file the form along with the accompanying documents, which she could not get, in some cases.

Thank you, Mr. Chairman.

OPENING STATEMENT OF HON. BILL BRADLEY, A U.S. SENATOR FROM NEW JERSEY

Senator BRADLEY. "Longer than a Top Secret security clearance." That might be a theme that we could establish here.

(Laughter)

Senator BRADLEY. Ms. Matula, how many States have taken advantage of the 185 percent of poverty level?

Ms. MATULA. The 185 percent of poverty has just been enacted in December. A number of States have yet to have their legislatures meet to appropriate funds. Three are on the seriously-considering list, and I believe six have enacted it. But they must have been anticipating it and have had the fortune of good timing, with the legislature in place to do so so quickly.

Senator BRADLEY. What do you see as the limits on State spending for expanding Medicaid eligibility?

Ms. MATULA. I think it depends on what the State's revenue picture is. If it is particularly depressed, their interest in going further may be hampered. I am thinking of the oil States and such that have had economic downturns.

But we, too, believe at the State level that the money invested here is money saved, and we don't think of it as just increased costs to the program. In the absence of the prenatal care, the children will qualify for lower levels of Medicaid eligibility, because they will have run up $30,000 and $50,000 intensive care bills their first month of life. We would prefer to pay for it up front than after the fact.

Senator **Bradley**. So, what you are saying is that the States really should expand Medicaid eligibility to save money.

Ms. **Matula**. Yes.

Senator **Bradley**. What about mandating continuous coverage and presumptive eligibility?

Ms. **Matula**. Well, it is optional.

Senator **Bradley**. I know. But what about mandating it? Do you see any strain that might result?

Ms. **Matula**. No. In terms of continuous eligibility, it saves administrative dollars by not having to reapply in six months. Many of these women would just be at the point of reapplication at the time that they would be delivering the baby. So there are almost no costs there for States. There would probably be a savings.

In terms of mandating presumptive eligibility, I don't know how States would react, because States' eligibility systems differ so widely. Some are State-administered eligibility systems, and it is easy to enact a mandate. In other States it is county or local administered programs. And I am sure you can appreciate a State's reluctance to accept a mandate from the Federal Government that it must impose on a locality.

Senator **Bradley**. So you think, both on mandatory continuation of coverage and on the expansion of eligibility, that really those save dollars; and on the presumptive eligibility, the problem there you see is more an inter-governmental problem?

Ms. **Matula**. Perhaps, yes.

Senator **Bradley**. Does anyone else on the panel want to add to what Ms. Matula has said?

Ms. **Botsonis**. Yes, Senator, if I may.

In Texas right now a woman who has income up to 34 percent of the Federal poverty level now qualifies for Medicaid. That is why we are pushing so hard for the 100 percent coverage on Medicaid.

Raising that—and, Senator Chafee, this will respond somewhat to your question, too—raising that eligibility requirement by 66 percent will no doubt cause a flood of the number of women who are coming in for care.

But since Texas now accounts for approximately one in every four poor, uninsured births in the Nation, we feel like that is certainly money well spent. We are looking at raising the eligibility levels from $226 for a family of four up to $706 for a family of four, which still may be considered by many criteria inadequate.

Senator **Bradley**. Two hundred and—what did you say?

Ms. **Botsonis**. Two hundred and twenty-six dollars for a family of four is the ceiling at present, at 34 percent of the Federal poverty level.

Senator **Bradley**. Two hundred and two dollars per what?

Ms. **Botsonis**. For the family of four.

Senator **Bradley**. Per month?

Ms. **Botsonis**. Yes, per month.

Senator **Bradley**. So in Texas, if you make more than—what? Twenty-five hundred dollars?

Ms. **Botsonis**. That is correct.

Senator **Bradley**. You don't get Medicaid if you are a poor, pregnant woman?

Ms. **Botsonis**. That is correct.

Senator **Chafee**. Twenty-five hundred dollars what? A year?

Ms. **Botsonis**. A year.

Senator **Bradley**. Twenty-five hundred dollars a year.

Ms. **Botsonis**. Yes, sir.

Senator **Bradley**. And you say 34 percent of the eligible population receives Medicaid.

Ms. **Botsonis**. The Medicaid eligibility level is 34% of the Federal poverty level. And as I say, that is what contributes to the one in four births to poor, pregnant women in our Nation that occur in Texas.

Senator **Bradley**. So you are saying, if we were able to expand this to 100 percent of eligibility——

Ms. **Botsonis**. That would raise that income level to $706 a month.

Senator **Bradley**. And because of the access to health care, that would also save money in the long term.

Ms. **Botsonis**. Yes, that is correct.

Senator **Bradley**. It seems to me that in this Catastrophic Health Bill right now we are taking care of all elderly below poverty, and in terms of pregnancy services we are taking care of all women below poverty, and we are also taking care of children up to age one. It seems what it leaves, as a big, vulnerable group of people in the society, are poor children above one but below five that are not covered. Is that not correct?

Does anyone want to talk about that problem at all? I mean, don't you think that this should be a priority of coverage? Let us say the Catastrophic Health Care Bill passes, and it embodies all of those expansions, in terms of 100 percent eligibility for pregnancy services, it takes care of the elderly and up to one year of age. What about up to the age of five?

Ms. Rosenbaum, I know you have been extremely helpful in this whole process, so maybe you can fill in the gap here.

Ms. **Rosenbaum**. As we mentioned before, the statistics on private insurance coverage today are such that it is evident that if Congress doesn't step forward with Medicaid coverage, there simply is no coverage.

About 12 percent of poor children have employer-provided insurance, and virtually no children have anything else. A few have some VA coverage.

The drop has been about 25 percent for those children since 1980 alone.

Senator **Bradley**. The drop?

Ms. **Rosenbaum**. The drop in the percentage of poor children with any employer coverage—which at a high was under 20 percent—is now down to about 12 percent.

Even if a bill such as S. 1265 mandating employer coverage were to pass, we think that that bill has enough gaps in it so that huge numbers of low-income children, not to mention near-poor children and children with moderate incomes, would still be without coverage.

There is a tremendous need for a very basic public plan exactly analogous to Medicare, structural pieces of which now have popped up in various measures passed by Congress.

You and Senator Chafee, in different measures, have introduced the notion of a sliding premium—the notion of covering near-poor persons, the notions of pegging Medicaid eligibility to criteria that have no relationship to welfare eligibility—although, as Barbara mentioned, that is far from finished.

These are all the kinds of structural breakthroughs that we have to speed up, not just for children up to age five, I would argue, but, as Dr. Perrin pointed out before, for children up to age 21.

Senator **Bradley**. Let me ask the panel if each of you would be in favor of mandating Medicaid coverage for children up to age four, poor children up to age four, or five, in order to establish the principle beginning, I would say, after January 1, 1988—all children born after January 1, 1988.

Ms. Rosenbaum?

Ms. **Rosenbaum**. Yes, we would certainly be in favor of that.

Senator **Bradley**. Dr. Golden?

Dr. **Golden**. Yes.

Senator **Bradley**. Ms. Botsonis?

Ms. **Botsonis**. Yes.

Senator **Bradley**. Ms. Matula?

Ms. **Matula**. Yes. This is up to 100 percent of poverty?

Senator **Bradley**. That is right.

Ms. **Matula**. I would hope by next year we will all be doing it. But yes, I would agree with that.

Senator **Bradley**. Thank you very much.

Senator Daschle, do you have any questions for this panel?

OPENING STATEMENT OF HON. TOM DASCHLE, A U.S. SENATOR FROM SOUTH DAKOTA

Senator **Daschle**. Mr. Chairman, in the interest of time, I think I will limit it to just one.

Much of the information I have heard from this panel in regard to eligibility is just outrageous. I guess I wasn't aware that the circumstances were as dramatic as you have described them.

Senator Chafee's question pertaining to the length of the form that one has to fill out, and Ms. Rosenbaum's response that it would probably take the entire term of a pregnancy to adequately fulfill the requirements has to be addressed.

My question would go along those lines.

In addition to expanding eligibility, the whole question of access to enrollment, especially in rural areas, has to be addressed a lot more effectively. Could any one of the members of the panel enlighten us a little bit in regard to what the barriers currently are, particularly in rural areas, and how we might strike them down?

Ms. **Matula**. Are you talking about barriers not related to the income requirements? Do you mean routine?

Senator **Daschle**. That is right. For example, in a rural area, one of the problems we have is the distance required.

Ms. **Matula**. Certainly, transportation.

Senator **Daschle**. I mean, a poor woman can't travel, especially in the wintertime, nearly the length of distance it often takes simply to get the form.

Ms. MATULA. Transportation not only to a site of eligibility but also to a provider has been a problem.

Senator DASCHLE. Let me just ask you, in that regard, can one apply for one of these 50-page forms in Hawaii by mail?

Ms. ROSENBAUM. I was just going to say, the obvious answer is a mail-in form, and if you whittle down the eligibility requirements to what they should be—which is if you are pregnant, if your stated income is below a certain level.

One of the big problems right now is just the task of evaluating what somebody's income is. It is a very long, arduous task. That could be whittled way back to a much more simple income affirmation.

There is no reason why you shouldn't be able to mail in an application form. It certainly helps to have presumptive eligibility and out-stationed workers at satellite clinics; but ideally the answer would be, I think simply to be able to apply at schools, and supermarkets, places where you could get an application, fill it out, and send it in. That is not common today.

Senator DASCHLE. It is not common. Is it prohibited?

Ms. ROSENBAUM. Actually, the only aspect of the Medicaid application process that is required right now under Federal law is that the welfare department make the eligibility determination. Where you apply, the form in which the application proceeds, and a variety of other factors affecting the accessibility of the program are up to States. So States now are experimenting with all kinds of simplifications.

Ms. MATULA. Do you know that one of the basic requirements of any eligibility system, no matter how simplified, is that you must have the Social Security Number and that the Social Security Administration has ceased allowing us through our social service agencies to send for those numbers? That means the client, by Federal regulation, now has to go to yet another place to apply for a Social Security Number?

Senator DASCHLE. Physically has to be there?

Ms. MATULA. That is right.

Senator DASCHLE. Can someone do it in his or her behalf?

Ms. MATULA. We used to do it for them, and we can't now.

Senator DASCHLE. Just to clarify that, can someone else go on behalf of the person?

Ms. MATULA. No.

Senator DASCHLE. They have to be there personally?

Ms. MATULA. They can go and apply for Medicaid on behalf of someone. They can have a relative. But not for a Social Security Number.

Senator DASCHLE. Well, I know we have another panel. I thank the respondents for answers to my questions, and thank you for the time.

Senator BRADLEY. Thank you very much, Senator Daschle.

Senator CHAFEE. Mr. Chairman, I would like to ask one quick question, if I might, to the panel.

Senator BRADLEY. Yes, Senator Chafee, by all means.

Senator CHAFEE. If you could, give very brief answers, because I recognize we have a panel after this.

Is physician refusal to accept Medicaid patients a problem?

Ms. **Rosenbaum**. It is an enormous problem. It is not an insurmountable problem. In pediatrics, in particular, I think it takes relatively low-level reforms to the program to make a change.

In obstetrics, if you talk to obstetricians for any length of time, what you discover is that some of the very issues that we have raised today, that are such a problem for the beneficiaries, are a problem for the obstetricians, particularly the issue of this continued eligibility.

A recent study indicated that there is a 40-percent turnover rate between the time a women who is pregnant starts her pregnancy and the time the baby comes.

Senator **Chafee**. A 40-percent turnover rate with what?

Ms. **Rosenbaum**. Forty percent of the women who were on the program at the beginning will disappear by the time their babies are born.

Senator **Chafee**. And why is that?

Ms. **Rosenbaum**. Physicians are loathe to take patients whose source of payment can't be guaranteed through the end of the pregnancy. Also, of course, the issue of malpractice liability. It is absolutely untrue that lower income women sue more; they probably sue less.

Yet, on the other hand, to the extent that we need to think about, whether certain forms of physician behavior—which is what tort law is all about—should be regulated through a tort system or not, is a major issue for debate.

Senator **Chafee**. Now, the next question is, is there a shortage of physicians in the community health centers? And if so, what should we do about it? All in one minute.

Ms. **Matula**. The Public Health Service has been cut back tremendously.

Senator **Chafee**. The what?

Ms. **Matula**. The Public Health Service, which places physicians in underserved areas has been cut back tremendously, and I would advise you ask them about their plans.

Dr. **Golden**. The National Health Service Corps is gone, in effect, now, and it was one of the few programs that really worked.

Ms. **Matula**. Yes.

Senator **Chafee**. What about if we excused the loans physicians had made during their medical school for service?

Ms. **Rosenbaum**. That is the new Corps program, is a loan forgiveness program, and the hope is that it will be quite effective in recruiting.

Senator **Chafee**. That is in effect now, is it?

Ms. **Rosenbaum**. We would love to see it expanded.

Ms. **Botsonis**. But still, we have found in the Texas Panhandle, which is primarily a rural area, that it is not a maldistribution of physicians as much as it is a maldistribution of providers who will accept Medicaid patients.

We have many communities which have an adequate number of physicians, but none of those physicians within the community will accept Medicaid patients; so, these patients have to travel great distances for care, if they receive care at all.

Senator **Chafee**. Do you mean the physicians won't accept the Medicaid patients?

Ms. BOTSONIS. That is correct.

Senator CHAFEE. Why? Because of what Ms. Rosenbaum said?

Ms. BOTSONIS. Well, part of it is what Ms. Rosenbaum said, they are afraid to take on these patients because, even when their eligibility has been discontinued, the physicians themselves have an obligation to continue to see these patients. And it is a situation where they cannot just abandon patients who are no longer eligible for coverage, particularly if these women fall within the criterion of high-risk pregnancy. Once the providers have identified the problem, then they have a moral and legal obligation to continue to see this woman, whether or not she is covered by Medicaid.

Senator CHAFEE. All right. Well, thank you.

Mr. Chairman, thank you. We certainly have got a lot of problems here.

Senator BRADLEY. Thank you, Senator Chafee, and that means that we will be able to do some good work.

Senator CHAFEE. Every problem represents an opportunity.

Senator BRADLEY. Our third panel consists of Emery A. Johnson, M.D., M.P.H., Assistant Surgeon General, Retired, U.S. Public Health Service, and former Director of Indian Health Service, of Rockville, Maryland; and Ellen Peach, M.S.N., C.F.N.P., Consultant, National Rural Health Association, of Richmond, Virginia.

Welcome to the subcommittee, and please begin. I will ask Senator Daschle if he wants to chair the rest of the hearing.

Thank you, and please begin your testimony.

STATEMENT OF EMERY A. JOHNSON, M.D., M.P.H., ASSISTANT SURGEON GENERAL, RETIRED, UNITED STATES PUBLIC HEALTH SERVICE, AND FORMER DIRECTOR, INDIAN HEALTH SERVICE, ROCKVILLE, MD

Dr. JOHNSON. Thank you, Mr. Chairman.

I have a prepared statement that I would like to submit for the record, then I would like to just very briefly summarize it.

Senator DASCHLE. Without objection, that will be done.

Dr. JOHNSON. The American Indian and Alaska Native People have a very unique relationship to the United States, a government-to-government relationship which is based on the Constitution, implemented through treaties and laws over the years, supported consistently by Supreme Court decisions.

It is a very difficult, complex issue many times, but I find it easier for all of us to understand by explaining that, really, what happened is that the tribal governments in the past sold the land to the Government of the United States in return for certain payments and services. One of those services was health care.

So, in effect, the Indian Nations paid for a prepaid health care plan, and it is the responsibility of the Federal Government to continue those payments in the form of health care.

We also have to remember that Indian People—Alaskan and Native American People—are also citizens of the United States and, as such, are entitled to participate fully in all federal programs and State programs on the same basis as any other citizen.

The Federal mechanism to provide this care, to pay for this prepaid health care plan, has been the Indian Health Service, which was founded in 1955 through transfer from the Bureau of Indian Affairs.

During this little more than three decades, there has been some remarkable improvements in health care of Indian People.

Early this morning, we heard people talking about, in infant mortality, the concept of giving passports, the concept of making sure that every pregnant woman knew what kind of health care she needed, and I think one of the witnesses even talked about people on motorcycles going from house to house to provide service.

That basically has been the kind of priority that the Indian Health Service had, the concept that we must provide access to health care, that the health of mothers and babies is a priority.

At the time of the transfer, the maternal and infant mortality rates of Indian People was two to three times higher than that of the general population. Today it is down at the same level. Part of it has been the priority, part of it is that we don't have a bunch of forms—40-50 pages of forms to fill out. Presumptive eligibility? You come in; you are taken care of.

The idea of home visits? The community health representatives, people who live in the community visit the homes, they know who is pregnant, and they encourage them to come in for care.

I might point out that this is the kind of program that this Administration has attempted to eliminate over the last seven year but the Congress, in its wisdom, has continued to fund. It is the kind of, I think, pennywise and pound foolish attempts to save money. And we have heard a number of comments this morning about how good prenatal care saves money in the long run.

Now, we must point out that there are still massive burdens of ill health in Indian communities, and that these national averages I am talking about are just that—averages.

We have areas where the circumstances are not that good. In South Dakota and North Dakota, for example, we have infant mortality rates that are twice the average Indian infant mortality rates. And we have other high incidence of disease, diabetes for example, which has an effect on the health of mothers and babies as well.

The way we have dealt with this—and I must point out something that I don't think this committee normally wants to talk about—the Indian Health Service from the beginning has been rationing medical care. We don't want to talk about that. As a physician, I certainly don't want to be involved in the rationing of medical care; but the resources that have been made available have required the rationing of medical care.

I think these improvements are even more remarkable when we consider that this has been done in a population that suffers with all of the problems of poverty, high risk, poor employment, poor educational opportunities, transportation problems, and so forth, and then the rationing of medical care; and yet, these improvements have taken place.

There is a system out there, a partnership between the Federal Government and Indian People, that shows that it can work. We do have a model in this country of how we can deal with infant mortality, and I would encourage this committee to take a look at how the Indian Tribal Governments and the Indian Health Service have dealt with this issue of child health.

Senator DASCHLE. Thank you, Dr. Johnson.

[Dr. Johnson's prepared statement appears in the Appendix.]

Senator DASCHLE. Ms. Peach?

STATEMENT OF ELLEN PEACH, M.S.N., C.F.N.P., CONSULTANT, NATIONAL RURAL HEALTH ASSOCIATION, RICHMOND, VA

Ms. PEACH. I am Ellen Peach, and a family nurse-practitioner. Although I am now from Richmond, Virginia, I spent 15 years in Idaho delivering health care to mothers and babies in a community health center system, then was involved in developing a system for pregnant rural adolescents, and now have studied rural systems in rural counties that we had selected in four States—Louisiana, Texas, South Carolina, and Montana.

The experiences that I had in going to these four States were certainly wonderful. We were looking at four counties that had had improvement over 15 years in their infant mortality rates. I got to experience decorated oil pumps in Lewing, Texas, and flew from Billings to Wolf Point, Montana, in a flight where the main question was not "aisle or window?" but "how much do you weigh?" So it was an interesting small plane ride.

The rural problems that we are looking at: Sixteen percent of all non-metro live births are to adolescents in rural areas, as opposed to 12 percent in metro births. So, one of the things we are looking at is a higher teen birth rate in rural areas. That is something, on the bad news side of it, that none of the four counties are dealing well with.

The good side? No miracles really happened in these little counties, but in some cases the maternal and infant health status indicators changed for the better, not quite reaching the 1990 objectives set out by the Department of Health and Human Services. There is still much room for improvement in each of these counties, but there has been improvement.

The following changes occurred in the past 10 to 15 years in the counties studied:

There has been placement of publicly funded physicians or certified nurse-midwives over the past decade.

In Roosevelt County, Montana, there are two National Health Service Corps placements, and I am glad to hear Dr. Johnson talk about the Indian Health Service physicians who provide care to a majority of the county residents, most of whom are members of the Fort Peck Indian Reservation.

In Caldwell County, Texas, the two young physicians who are providing most of the in-county obstetrical services are part of the Texas Medical Scholarship Payback System. One has served his obligation and is staying, and the other is thinking about it.

In three counties, some arrangement for in-county obstetrical consultation has been made, or obstetricians have actually been brought in.

There have been perinatal transport systems and training in many of the small level-one hospitals.

In Roosevelt County, Montana, Trinity Hospital in Wolf Point has trained all of the registered nurses there in advanced cardiac life support, and the Montana Perinatal Series, which supports in-trouble newborns or mothers at risk in labor.

There is a high utilization of WIC service, and low income pregnant women identify WIC as the first service to seek in these four counties.

Program boundaries are porous. By that, I mean that when you go in for a WIC visit you might also be assessed for risk for premature labor at the very same visit. I have heard the co-location and the coordination of service issues mentioned several times.

Systems of case tracking and management have either evolved or have been formally implemented in some of the counties. Data is collected and used.

Community concern and leadership about the problems in maternal and infant care have developed. In 1979, in Clarendon County, South Carolina, the fifth poorest county in the State, a community perinatal taskforce was started out of a broad-based concern for the high infant mortality rate in the county. The taskforce developed an intensive perinatal education program, which swept through the schools, the churches, and the garden clubs, and won an award in 1982 in the State for innovation and dedication in the area of public health. There were individual and collective efforts to see that mommies and babies that needed care were somehow channeled into care.

The one item that I would like to mention here before closing is that teen pregnancy, once again, is either not addressed or just being addressed in these areas. Schools have not been used effectively in identifying and forming a partnership with public health departments in these areas.

Teens don't do the correct thing just because they have the knowledge; something else has to go on with them, especially in rural areas where the distances are just fantastic. And the co-location of service in two of the counties I traveled to, in South Carolina in particular and also Roosevelt County, Montana, everything was literally in one city block, and sometimes in the same building, so you didn't have to go from Medicaid on one side of the county to WIC on the other side of the county; it was one-stop shopping, if you will, for the women who were pregnant and also for the infants.

Thank you very much.

Senator DASCHLE. Thank you, Ms. Peach.

[Ms. Peach's prepared statement appears in the Appendix.]

Senator DASCHLE. Dr. Johnson, as you may know, this is a second in a series of hearings we are having on this. Dr. Windom, the head of the Public Health Service, indicated at the last hearing that he didn't feel that access to care was a problem in this country, that there is adequate access.

From what I could tell in your comments and from what I know you to believe, your position is in conflict with that. Could you elaborate a little bit, especially as it relates to the Reservations?

Dr. JOHNSON. I think that access is a relative term, Senator Daschle. Certainly, if you look historically, access on Indian Reservations is substantially greater today than it was 25 or 30 years ago; but that still doesn't lower the distance between some of the remote villages and your health program. It doesn't cover the fact that you have inadequate automobiles, the roads are atrocious, telephones are unknown in some of the villages. Certainly in the winter, with the bad weather, and in the spring with the mud, and so forth.

That is why I think it has been so important to try to turn the access around. Instead of saying that the access has to be in the hospital or the clinic, to try to have an access point in the village. I think that is what was done with the Village Health Aid in Alaska, where every village has someone who is trained, a native in that village trained, to diagnose and treat a disease, and with telephone or radio contact with the physician back in the base hospital or the base clinic. That is what the CHRs have done, not only in providing health education and motivation and identifying these people but in helping them get into the kind of care they need.

As I say, there is access there, but, Senator, it is access that is constantly under attack. This kind of access doesn't seem to be a very high priority. It is something that our friends in the Office of Management and Budget can talk about as being "peripheral," as being "non-priority"; and yet, to me, that is one of the most critical factors that we have had in making this change in infant mortality.

Senator DASCHLE. The question is relative in more ways than one. It is relative in the sense that, once you get there, what have you got in terms of adequate attention and service?

The Rosebud Pine Ridge experience in the last couple of years is a primary example of that. I just had a meeting with the IHS doctors about a month ago. They indicated that over the last year more than 800 babies were born on those two Reservations; 75 percent, according to these doctors, were high risk deliveries, and we had one OB-GYN. And there have been times when we have had no OB-GYN. The doctor who was there was sick on occasion, and when he was gone there was no one. So they delivered their children, basically, on their own.

I mean, that is unbelievable. It is 1988. We are talking about circumstances and a situation that parallels that which many people in rural areas had 100 years ago, finding a neighborhood assistant to provide for the delivery of a child.

Is that common?

Dr. JOHNSON. Sure.

Senator DASCHLE. Does that relate to your experiences in the Indian Health Service?

Dr. JOHNSON. Again, here is the frustration, Senator Daschle. When we were working with the Rosebud Tribe on the hospital, there is not an obstetrician between Yankton and Rapid City, and that is—what?—360 miles, or something like that. Clearly, we wanted to have potential for obstetrical services somewhere in there. The Administration refused to allow the construction of a surgical suite in that hospital, which is essential if you are going to have obstetric care.

So what we are doing at Rosebud today is hauling these people off at high risk to Yankton or Sioux Falls or Rapid City, or wherever.

Fortunately again, the Congress in its wisdom has made provisions so that we are going to have the surgical suite in the Rosebud Hospital, but it was over the objection of the Administration that is supposed to be trying to support the reductions in infant mortality. How can we do that if we can't have those kinds of skilled people with access?

So it is both. Yes, it is access for the people to the facility, but you have got to have the skilled people.

Here again, just for a moment, if you can't maintain the level of quality of your health system, so what if you get there? And how do you keep high quality people if they find their support eroding, if we have budget proposals to cut our nursing staff by 10 or 12 percent, or cut our contract support by 25 percent?

When you have things like that, the physician sits out there or the nurse sits out there and says, "What's the use?" As one of the earlier witnesses said, physicians will go to these places when they feel they can make a contribution and they can create change. But if you are constantly struggling to hold on, until we come to grips with a commitment to honor the Federal Government's treaty and to maintain that basic health system, then we are going to continue this constant struggle.

Senator **Daschle**. You said that we are rationing health care delivery right now. Elaborate a little bit, if you would. To what degree do you think that rationing exists today?

Dr. **Johnson**. Well, it is a mixed bag. If you are in a place where you have a full medical center—Alaska, the Phoenix area, or the Navajo area—most of the things that you need to get done—surgery and so forth—will get done, because you have the specialists inhouse, and it is relatively less expensive to do it inhouse.

The major problem comes—and unfortunately it is in the greatest part in the Indian community—where you don't have inhouse capability, and you have to send it out to contact health services, send it out to the private sector for surgery, for example, or for some kind of specialty care.

The contract health service budget has been a rationing process, as I said, from day one. We have had over the years lists of unmet surgery longer than your arm. At one time, again, we looked into Rosebud. There were several hundred cases that had been backlogged, cases that should be done and ought to be done; and yet, they can't be done.

Senator **Daschle**. Several hundred in a population of a few thousand, correct?

Dr. **Johnson**. Probably about eight thousand, roughly.

Senator **Daschle**. Yes.

Dr. **Johnson**. And that is not by really looking for them. In other words, there was no purpose in trying to count up everyone, because there was no hope to deal with it, anyway. But this is just what you knew.

Senator **Daschle**. We are running out of time, and I have a lot of things that come to mind here.

One concern that I have relates to the Commissioned Physician Corps. Why isn't it working? Why can't we get Commissioned Physician Corps doctors to come to Pine Ridge and Rosebud, to come especially to the Aberdeen area?

We have more doctors in Rockville than we have on most of the Reservations, especially in Aberdeen. That entire Aberdeen area I am sure has fewer doctors than Rockville does. And I don't know in the bureaucracy itself of one medical performance provided there. Why isn't it working? How can we force doctors who benefit from the Commissioned Physician Corps to fulfill their requirements and responsibilities in serving rural needs?

Dr. JOHNSON. Well, I think we can. My concern, Senator, is that we need to do it with some discretion. My sense always was that I would really prefer to have physicians serving who wanted to be there. I think if you force someone who just simply doesn't want to be there, I am not terribly certain how well served the population is going to be.

I would prefer to address it from the other option, and say let us create the environment, the challenge, the opportunity for a physician to come out and to practice good quality medicine, and to make a contribution, and to see change.

Senator DASCHLE. I tell you, given the choice of Rockville and Pine Ridge, if you just say to people, "Look, you are on your own; you make the decision," they just——

Dr. JOHNSON. I am not talking about making your own decision; I am just saying that there are ways other than simply saying, "This is where you go."

One of the ways for example, is to say, "If you want to come to a place like Phoenix or Albuquerque or Santa Fe," or something like that, "you will get there by way of Pine Ridge." Okay?

Ms. PEACH. Senator Daschle, could I also respond to that?

Senator DASCHLE. Yes, Ms. Peach.

Ms. PEACH. One of the things that I understand the National Health Service Corps is looking to is a 33-percent cut this next year. I do agree with Dr. Johnson that one wants physicians who are committed to working with the population, as to where they are in "payback." However, the smaller your pool, and the more sites you have, I am not really sure how you are going to do that.

Senator DASCHLE. Well, haven't there been times in the past when we have more effectively addressed this problem than we are today? The impression I have is that there was once a system that worked, perhaps not to our satisfaction, but worked a whole lot better by any objective analysis than what is working today. So perhaps it is all "relative," as we get back to that term; but there have to be ways that we can make this system work a whole lot better than it does today.

In what brief time we have left, could you address that? I like your idea of setting up some criterion by which, in order to go to paradise you have to go through purgatory. I don't know what the answer is.

Elaborate, if you could, and then we will close out the hearing—either one of you.

Dr. JOHNSON. One of the things, Senator, is that, rather than a single solution, a broad series of initiatives. I think if you look at S. 1475 that was passed by the Senate fairly recently, we are looking at a whole series of things that one can do. One has to do with the payback and the kind of support:

The idea of a sabbatical, allowing a physician who is practicing in remote areas to get away for continuing medical education, and doing research and so forth before he comes back; the idea of challenges to Tribal Governments to recruit and retain, I don't think it is recruitment that is the problem; my contention for years has been its retention. If we could get that doctor at Pine Ridge to stay not just two years but to stay three years or four years or five years. And this has worked.

For example, the Hopi health program in Arizona: We have had people standing in line to get there for years, and every one of them board-certified. Three or four people would have to come and be interviewed by the Council before they could come there. And that is as isolated as any place in South Dakota.

But they came because the community took a responsibility. Abbott Sekaqnaptewa, the Chairman, and the Council, said, "We have the responsibility here." And in S. 1475 we have a provision to try those kinds of experiments.

I think much of the solution is going to come out of local communities, not necessarily something decided in Washington or Rockville. I like that kind of challenge to the leadership because, if this thing works, it is a real partnership between the tribal governments and the Federal agency. I think we have some good examples to show how that works, but we need more support for that.

Senator DASCHLE. Ms. Peach?

Ms. PEACH. I think another thing is to look at some of the studies that have been done in physician retention in rural areas. One of them was out of the University of North Carolina on retention of pediatricians. I know that this is something that the committee has been very concerned about, in infant health and child health.

Pediatricians are more likely to leave a rural community when there is a high proportion of minorities who are subsequently extremely poor, low levels of insurance, competition among other primary care providers who don't seem to want pediatric services, as it were, distant hospitals, poor bookkeeping, and insufficient nonphysician health services.

That is where your Public Health Department, your Title V Maternal and Child Block Grant funding is so very important. Pediatricians need to know that there are WIC services available, that their immunization service is available, that these services are coordinated; because, otherwise, they wind up in the frustrating circumstance of knowing there is no way, no matter how good they are, that they can practice quality health care. So it is a far-reaching thing.

Health care, like politics, is ultimately at the local level. But in rural health care, in Reservation health care, it is the Federal programs that have an incredible impact on these little rural counties now.

Some of the suggestions that Dr. Johnson had, also making sure that structural barriers to coordination on the Federal level and State level to programs that should be working on the local level need to be looked at, and other things that came out of the rural research health agenda.

Senator DASCHLE. Well, I want to thank both of you.

I think that part of it, too, is not just OMB but the allocation of resources within the agencies, especially the Indian Health Service. We not only are rationing health care, but in my view right now we are rationing that small pool of resource that we actually have inappropriately.

I think the other districts, for whatever reason, are doing much better in terms of resources than the Aberdeen area is. As a member of the Indian Affairs Committee, I am going to be very sensitive to that balance in the future. I hope that we can reallocate and assist those areas that need it the most. You have enlightened us in this regard, and I appreciate it very much.

I am sure I speak for the whole committee in thanking both of you and in thanking those panels who have preceded you. This is a very difficult issue, and we are delighted that you could share some of your insights with us.

[The prepared statement of Ellen Peach appears in the Appendix.]

The Committee stands adjourned.

[Whereupon, at 1:05 p.m., the hearing was concluded.]

CHILDREN'S PRIMARY CARE AND CHRONIC HEALTH CARE ISSUES

THURSDAY, MAY 26, 1988

U.S. SENATE,
COMMITTEE ON FINANCE,
Washington, D.C.

The hearing was convened, pursuant to notice, at 10:05 a.m. in Room SD-215, Dirksen Senate Office Building, the Honorable Lloyd Bentsen (chairman) presiding.

Present: Senators Bentsen, Rockefeller, Daschle, Chafee, Wallop and Durenberger.

[The prepared statements of Senators Rockefeller, Chafee, Heinz and Durenberger appear in the appendix.]

The CHAIRMAN. Please cease conversation and take a seat, and this hearing will be under way.

This is the third and final hearing of the hearings being held on health care issues affecting children. Now, that is an area of great concern to this committee.

Earlier this week, the committee heard testimony about the need to improve the primary care services for children. I was particularly struck by the economic arguments that were made by the witnesses and some of the things that have happened to families in trying to care for these children.

I think today's failure to give America's children access to adequate and affordable health care is going to cost families, is going to cost health care providers, and is going to cost the taxpayers of this Nation millions. No, it is going to cost them billions of dollars, I think, in the future; and that is an expense that could be avoided if we invested our health care dollars wisely.

I think the arguments are equally compelling when we turn to the subject of today's hearings—children who become seriously ill, often with a chronic condition, who incur very large expenses. Now, that is an issue that affects all economic groups right across the levels of the economy.

Every American family is vulnerable to a high cost catastrophic illness. The parents of a catastrophically ill child suffer not only the untold emotional stress, but they can see their life savings wiped out by costs that are not covered by even the most comprehensive of health plans.

Yesterday afternoon, we finished the conference on catastrophic illness, but there we addressed the older citizens of our society. We have not begun to seriously address in any coordinated way the concerns and the problems of the chronically ill children, and I know that the number of those children is small; but for the parents of that child, it is 100 percent—a total involvement.

Now, the cost for that individual family can be devastating. It is estimated that there are 19,000 children who incur health care costs in this country—and listen to this number, 19,000 of them—over $50,000 a year.

Health care costs can become an issue even for families that obviously have incomes well above the poverty line. One in five children has no public or private health insurance. Of 37 million uninsured Americans, 12 million are children, nine million of whom are dependents of workers who lack insurance against any health care costs.

Today, we are going to hear from witnesses about the way in which the current patchwork health care system addresses the needs of seriously ill children in this country. The system has many components, and the components are generally good, except they really are not coordinated.

Medicaid for Low-Income Children, the Maternal and Child Health Block Grant Program, employer-sponsored health insurance that covers the majority of the nation's children, and Medicare for a small number of children with end-stage kidney disease. Our challenge is to strengthen those programs.

You are looking at a situation today where you can have a parent locked into a job because they can't afford to leave that job because they are afraid they can't get the insurance at the next one that takes care of that chronically ill child.

It is not an exaggeration to say that our children are our future, and it is up to us to invest in them. Otherwise, we can close our eyes to the growing problems of inadequate health care coverage for children. I think even in a time of budget constraint that we really have to face up to this one.

Our first panel will be Mr. Alexander R. White, Jr., Chief Executive Officer of the Santa Rosa Children's Hospital in San Antonio, Texas; Mr. Val Halamandaris, President of the National Association for Home Care, Washington, D.C.; Dr. Mark Swanson, Director of the University Affiliated Center of the University of Texas, Southwestern Medical Center at Dallas, Dallas, Texas; and Dr. William Hollinshead, President, Association of Maternal and Child Health Programs, Providence, Rhode Island.

If you gentlemen would come forward, please? Mr. White, if you would lead off, please?

Now, let me state we have other panels this morning and a number of witnesses, and we will have a time limitation. We will take all of your statements in the record; but we will have a time limitation of five minutes so we will have time for questioning. Now, if you would proceed?

STATEMENT OF ALEXANDER R. WHITE, JR., CHIEF EXECUTIVE OFFICER, SANTA ROSA CHILDREN'S HOSPITAL, SAN ANTONIO, TX., ON BEHALF OF THE NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS AND RELATED INSTITUTIONS, INC., ALEXANDRIA, VA

Mr. WHITE. Mr. Chairman and members of the committee, it is an honor to have the opportunity to testify before you today. I am Alex White; I serve as the Chief Executive Officer of Santa Rosa Children's Hospital in San Antonio, Texas. I also have been the Executive Director of the Texas Children's Hospital in Houston, and the President of the Children's Hospital Association of Texas.

Today, I am representing NACHRI, the National Association of Children's Hospitals and Related Institutions; and I am pleased to be able to say that the American Hospital Association joins NACHRI in supporting our recommendations.

I will submit my written statement for the record and briefly summarize it for you. I would like to call your attention to three points as the committee considers special problems of children with chronic health problems.

First, children's hospitals have extensive experience in caring for children with chronic illness or disability. Many of these children's chronic conditions often begin with a catastrophic experience of acute illness in our children's hospitals.

Second, the expenses for chronically ill child care, particularly those in our hospitals which have catastrophic illness, often exceed their insurance coverage, if they have any, and their financial means. And the chairman alluded to this earlier in his opening remarks.

Third, one of the most helpful actions Congress can take to ensure the availability of hospital care for these children when they are poor is to require States with strict limits on their Medicaid reimbursement to make exceptions for very sick infants.

I would like to develop each of these points for you. Let me begin with two stories.

The first is about Penny, a nine-year-old with cancer, from Eagle Pass in west Texas. Penny's family is poor enough to be eligible for Medicaid; however, Texas places strict limits on Medicaid reimbursement. Penny already had exceeded the coverage available to her under Medicaid.

Consequently, Medicaid did not cover the $63,000 in charges for her four admissions to Santa Rosa Children's Hospital between August and January of this year. The hospital will try to cover these costs of her care through charitable contributions and other resources.

My second story is about Lisa, a baby from Sugarland, which is a suburb of Houston. Lisa had bronchial pulmonary dysplasia, which is a chronic lung disease, a condition often found in premature infants.

She received care for several months at Texas Children's Hospital in Houston. When she entered the hospital, both her parents were employed; and they had insurance through their employers. However, Lisa's mother had to give up her job to care for her baby. Her father's insurance benefits were exhausted after paying

$290,000, but her health care bills eventually totaled nearly $440,000.

Penny and Lisa are not representative of all chronically ill children because most of them have moderate conditions, but these little girls are representative of the many chronically ill children seen in the children's hospitals.

That is because children's hospitals are specifically organized to care for very sick children, children with special health care needs, and children whose families often have limited or no incomes.

Texas Medicaid reimbursement limits place an extraordinary burden on hospitals like Santa Rosa Children's, which are committed to serving both the very sick and the very poor. About half of the children cared for at Santa Rosa Children's Hospital are Medicaid-sponsored; that is well above the average.

And about 75 percent of our total unreimbursed care is attributed to these Medicaid patients whose stays have exceeded the State's 30-day limit, the $50,000 cap, or whose reimbursement under the DRG scheme is much less than charges—less than costs as well.

Texas is by no means unique in placing strict limits on Medicaid reimbursement. In Alabama, it is 12 days; in Kentucky, 14; Mississippi, 30; Oregon, 18; West Virginia, 25. These kinds of limits have tremendous consequences for children's hospitals all around the country.

On average, Medicaid reimburses a children's hospital just 70 cents for each dollar of cost the hospital incurs to care for a sick child. As a consequence, children's hospitals are often forced to devote a substantial portion of their charitable contributions and resources to subsidizing Medicaid instead of expanding health care access to children without any insurance, as well as improving the quality of care.

As you will see in my written statement, we have given you a broad set of recommendations. However, I would like to focus on two specific changes in Medicaid which Congress now is seriously considering.

First, we urge the committee to seek Congress' adoption of the mandatory Medicaid eligibility for pregnant women and infants. This is an important step in providing health care where it is most likely to help prevent the development of chronic illness and disability among children of families with low incomes—again, a point made by the chairman early on.

Second, we also urge the committee to require every State with strict limits on its Medicaid reimbursement to make exceptions for a very special group of children—infants in the first year of life receiving medically necessary care in hospitals that already have a disproportionately large number of patients under Medicaid.

Both of these are very modest steps, but they are consistent with the improvements in Medicaid that this committee has initiated in recent years. It should be budgetarily feasible. It will benefit both chronically ill children and poor children.

I want to thank you again for your consideration. I will be glad to answer questions if I can. Thank you, Senator.

The CHAIRMAN. Thank you. I was on the Board of Texas Children's Hospital in Houston for several years and have had some experience in that area.

[The prepared statement of Mr. White appears in the appendix.]

The CHAIRMAN. Mr. Halamandaris, if you would proceed?

STATEMENT OF VAL J. HALAMANDARIS, J.D., PRESIDENT, NATIONAL ASSOCIATION FOR HOME CARE, WASHINGTON, DC

Mr. HALAMANDARIS. Thank you, Mr. Chairman. First of all, I would like to commend you for holding these hearings and to commend you in general for your leadership of the Senate Finance Committee.

I learned as a youngster that everything good came from Texas. I had an uncle who bought a quarter horse that was the most wonderful animal I had ever seen. I fancied a pair of boots that were just wonderful. I learned that anything good came from Texas; and now that I have seen your leadership of this committee——

The CHAIRMAN. You really know how to get to a fellow, don't you?

(Laughter)

Mr. HALAMANDARIS. I am all the more convinced of that fact. I am just reaching back to my past. In 1963, I sat in the chamber of the House of Representatives and heard President John F. Kennedy argue for the enactment of the Medicare Program. He talked about the fact that the elderly were sick three times as often and three times as long.

But what struck me—and I thought it was a little strange at the time—was that he said what was at stake was our very place in history. And then, he went on to say what was at stake was our very survival as a Nation; and he clarified that by quoting the historian, Arnold Toynbe.

Toynbe said that you could tell the greatness and the durability of a society by the manner in which it treats its frail children and its infirmed elderly.

In the same year, I sat in the gallery of the Senate chamber, and I heard Hubert Humphrey make the same point. He talked about the importance of taking care of those individuals, he said, were on the fringes of life—the elderly in the twilight of life, the children in the dawn of life—who were having problems—and the handicapped that he said were in the shadows of life.

So, I want to commend you for having these hearings. The National Association for Home Care has as its primary purpose the advancement of the interests of those individuals that Hubert Humphrey said were on the fringes of life.

Technology, Mr. Chairman, has given us a wonderful gift, a gift of another third of life, in the case of the elderly; in the case of young children, we have been able to save thousands of youngsters who previously would have died.

It used to be that three pounds was the absolute demarcation line. A child that was born with a birth weight of less than three pounds did not survive. In these days, we routinely save children of birth weights of less than two pounds.

So, we have been given a gift, but there are also responsibilities associated with that. You just heard my colleague point out the severe limitations that are available with respect to appropriate hospital care. I would suggest that that is true.

I would also make the point that there is even less in the way of home care available for children; and in many cases, that is what families prefer, and that is what is most appropriate for these small infants.

So, I would like to argue, Mr. Chairman, for a system that does the ultimate in keeping families together. There is no more important social value than reinforcing the American family, and making it possible for them to care for their youngsters at home should be our primary objective.

A few major conclusions from the report that our association provided on this subject some time ago: first of all, we found there are about one million children who are severely disabled, that there is a genuine health care crisis in America involving these children, the most severe of which are those who are respirator-dependent.

The second thing is that technology which created the problem in the sense of saving lives is also the solution—that technology which, until recently, had only been available in the hospital now has been miniaturized to the point that it is available at home.

And youngsters with severe disabilities, even those who are respirator-dependent, can be cared for at home. They can be in this room. They can go to school. They can be mainstreamed, instead of being isolated in the intensive care units of hospitals.

I would point out further that there are severe emotional problems associated with the care of disabled youngsters. There is nothing that will shatter a family more than having a youngster who is in the hospital and having to visit that youngster day in and day out.

As you know, at least one parent has to be with the child all the time and, therefore, cannot work; and there is severe stress associated with that.

I also would like to point out that our major medical plans—insurance and so forth—do not adequately provide coverage. I have seen a number of major medical plans—good ones—exhausted in the first year of coverage. And that is something that I think we need to address.

If I was looking for a solution, Mr. Chairman, and I could wave a magic wand and give you one answer, I probably would look to something on the order of the Medicare Program covering these chronically ill children along with the disabled elderly.

I believe that the real issue is functional disability and not age, and that the Government should intervene and help people; but I also believe we need a partnership between the private sector and the public sector. The problem is so large that it can't be solved simply by the public sector. We need the expansion of private health insurance coverage as well.

I believe your committee can address these issues, and I am sure under your leadership, Mr. Chairman, you will. Thank you very much.

[The prepared statement of Mr. Halamandaris appears in the appendix.]

The CHAIRMAN. Thank you. Dr. Swanson?

STATEMENT OF MARK E. SWANSON, M.D., M.P.H., DIRECTOR, UNIVERSITY AFFILIATED CENTER, THE UNIVERSITY OF TEXAS, SOUTHWESTERN MEDICAL CENTER AT DALLAS, DALLAS, TX

Dr. SWANSON. Mr. Chairman and members of the committee, I am Dr. Mark Swanson, a pediatrician and Director of the University Affiliated Center, part of the University of Texas, Southwestern Medical Center at Dallas, Department of Pediatrics.

Thank you for giving me the opportunity to testify today on the health care needs of children with chronic illnesses. Although my brief remarks will address a number of specific issues, the singlemost significant point I want to make today is this: The lack of coordination among State and local administering agencies, service providers, and third party payers is one of the primary barriers to the provision of health care, not only to chronically ill and technology-dependent children, but to children as a whole and of all ages.

Services for mothers and children are traditionally disbursed among various States agencies with, in many cases, overlapping and contradictory mandates and responsibilities. According to a recent report to Congress on technology-dependent children, parents—particularly those of children with special health care needs—are faced with the task of, first, identifying available programs in their area and, second, successfully navigating the maze of programs in order to assemble a complex package of services for their children.

Clearly, Mr. Chairman, the primary focus of Federal policy making in this area must be to provide collaboration between, on the one hand, the providers of medical, educational, and social services and, on the other hand, public and private funding agencies.

Recently, a group of major organizations representing professionals, child health advocates, and State agencies gathered to develop a comprehensive legislative approach to the problems I have just described through proposed amendments to the MCH Block Grant.

This joint proposal, which is still in the drafting stage, attempts to bring cohesion to our existing maternal and child service delivery system at the two levels where it counts the most.

First, the recommendation would mandate the development of a State-wide maternal and child health service delivery plan, which entails the establishment of clearly defined objectives and the identification of both unmet health care needs and underserved populations. Unlike the existing system, the planning process would explicitly involve the most important providers, consumers, and third party payers in a given State.

Second, on the level of the individual child, the group endorses a coordinated family centered care coordination initiative to be administered by the Title V Programs for Children with Special Health Care Needs.

On behalf of the American Association of University Affiliated Programs, I strongly support these proposals and urge your consideration and approval once they are formally submitted. The same issues I just described affect the two populations of children with chronic illness that I wish to spend the remainder of my time here discussing—technology-dependent children and handicapped infants and toddlers between birth and three years old.

In recent years, certain Federal and State programs have attempted to facilitate the transfer of children requiring ventilator and similar high technology from tertiary health care centers and hospitals to community and home-based settings. This policy shift resulted from research which revealed dramatic improvements in the health and developmental status of chronically ill and handicapped children who remained at home.

However, the maintenance of a technology-dependent child in a home or community-based environment requires the development of a considerable support system, including physical therapy, speech, language, pathology, occupational therapy, nutritional consultations, and the services of a social worker.

Moreover, physical modifications to the home itself are often necessary along with arrangements to mainstream the child into a regular classroom. The University Affiliated Center in Dallas is addressing these issues at several levels.

At Children's Medical Center, an infant education team has been organized with hospital and University Affiliated Center personnel to facilitate the transition of technology-dependent children from the hospital to the community.

Specifically, we are training both hospital personnel and community service providers in the realities of life outside the medical center for medically complex children and their families.

In addition, the UAC will provide technical assistance and training to the Texas Chronically Ill and Disabled Children's Bureau, as it has been charged with providing coordinated care to 200 technology-dependent children awaiting transfer from hospital to home.

In general, Congress did not intend Title V to address the broad policy questions outlined; however, through the Federal set-aside, it did provide the MCH Block Grant with the legislative mandate to deal with another significant impediment to the transfer of technology-dependent children into home and community-based programs the preparation of personnel.

Consistent with this need to foster an interdisciplinary interagency approach for each child and family, the Bureau of Maternal and Child Health should provide a focused, coherent, multiyear training program for community health care, education, and related services personnel.

And the requirement for such a program is definitely growing. A recent estimate suggested that 17,000 such technology-dependent children exist, and this was mentioned by previous speakers—a success story as a result of advancing medical technology and enhanced skill of the providers.

It is incumbent upon Federal and State policy makers to keep pace with the needed training and service programs that will allow these children to reach their maximum potential.

The chairman. If you would please summarize, Doctor?

Dr. SWANSON. In Texas, 34,000 children ages zero to three have established a developmental delay. In conclusion, the Federal and State agencies cannot stand aside from facing a manpower challenge that we confront as a Nation.

We propose a personnel development initiative through BMCH to assist States in planning for these programs. Thank you for allowing me to speak on these vital issues.

The CHAIRMAN. Thank you very much.

[The prepared statement of Dr. Swanson appears in the appendix.]

The CHAIRMAN. I would like to defer now to Senator Chafee for the introduction of the next witness.

OPENING STATEMENT OF HON. JOHN H. CHAFEE, A U.S. SENATOR FROM RHODE ISLAND

Senator CHAFEE. Thank you very much, Mr. Chairman. I appreciate that. Dr. Hollinshead is Director of the Maternal and Child Health Program in the State of Rhode Island. He is on the National Commission to prevent infant mortality.

He has provided real leadership in our State in connection with these matters that we are discussing here today. I want to pay tribute to you, Dr. Hollinshead, for the work you have done; and we are making significant progress in Rhode Island because of the fine work that you and the whole Department of Health are doing.

Thank you, and I am glad you are here. Thank you, Mr. Chairman.

The CHAIRMAN. Dr. Hollinshead?

STATEMENT OF WILLIAM H. HOLLINSHEAD, M.D., M.P.H., PRESIDENT, ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS, PROVIDENCE, RI

Dr. HOLLINSHEAD. Thank you, Mr. Chairman. Although I am not from Texas, having done my medical training in Minnesota and served for some years as Director of Family Health in Rhode Island, perhaps I can give a little different perspective.

(Laughter)

Dr. HOLLINSHEAD. The Association of Maternal and Child Health Programs is indeed heartened by these Finance Committee hearings, and we are pleased to share our recent experience in State maternal and child health programs.

We come to call for a renewed National commitment to assure better family health by the 21st century, and we will propose several concrete steps to be sure that that occurs. We come in the conviction that good maternal and child health programs are the foundation for growth and strength, not only of individuals and children, but for families, communities, and ultimately for the Nation.

Title V programs are unique in their comprehensive focus on child health, including especially the needs of children with special health care problems and in their responsibility to study and plan for the future of these systems and these children.

This commitment to data and planning is the foundation of maternal and child health leadership. Unfortunately, our other responsibility under the Act—to offer care to low income uninsured children—has in fact led us to address needs that are, especially in recent years, far beyond public health budgets.

And that attempt to fill gaps has sometimes weakened data, planning, and other fundamental public health responsibilities. Despite all that, since 1981, State MCH programs and programs for children with special health needs have led to expansion of prenatal services and the development of home care for technology-dependent children in many States.

In fact, the widespread success of recent Medicaid extensions and waiver programs for special needs children could really only have occurred with public health leadership in many of these States. In State after State, planning, training, standard setting, and often the direct management of these programs is dependent upon the Title V agencies.

Our agencies have another set of critical public health responsibilities which have to do with assuring the quality and content of maternal and child health care. I am submitting a more detailed review of these functions for the record, including a variety of State examples.

I want to conclude with our three major recommendations for the committee's consideration this year.

First, we believe America needs universal health care coverage that promotes healthy children. Our long-term goal must be simple, direct, universal coverage that assures a common standard of health care for all citizens, including preventive, developmental, care coordination, and catastrophic benefits.

In the near term, we support current proposals to strengthen employer-based family coverage, and we strongly endorse the Bradley-Waxman and Chafee Medicaid extensions now before the Congress. We clearly must include children in any initiative on catastrophic coverage.

Because we know from experience that better coverage does not assure good care in all environments, the Title V language should include explicit responsibility to establish standards for both coverage care and to evaluate outcomes in relationship to that coverage.

Second, America needs strong public health leadership for healthy children. We would recommend that America's health objectives for the year 2000 should be ambitious and comprehensive in their treatment of children's health.

We recommend convening a 1990 White House Conference on child and family health, to be sure our national agenda will get us to those objectives.

The Bureau of Maternal and Child Health and the Public Health Service should be charged, staffed, and funded to renew the Nation's data base on children's health and to support training and technical assistance for State programs.

We also support a mandated national system of integrated State maternal and child health plans and reports to include the assessment of unmet needs, services, and outcomes. These reports should be keyed to the health objectives for the year 2000.

Third, we believe America needs stronger State and local maternal and child health programs. Next year, this committee will consider new authorization levels for future years in Title V, and that will give us a golden opportunity to strengthen both the public health mandate and our information base for each population served.

The Title V mandate should still allow State and local programs to deliver direct services where that is absolutely needed, but we hope that coverage improvements will rapidly diminish that responsibility over the next decade.

Title V programs should be clearly designated as lead agencies for care coordination for children with catastrophic health care costs as proposed in S. 1537 and other proposals upcoming. Title V should strengthen its mandate and resources to offer preventive and primary care services for mothers and children not commonly covered by community clinical providers.

Conforming legislation and/or regulatory changes should be made in related programs, especially the Medicaid and Education for the Handicapped Act.

All of these challenges will require a new national commitment to make children's health our highest priority for the next decade. We are eager to join the committee and our many friends to bring this Nation the healthiest children in the world by the year 2000.

The CHAIRMAN. Thank you.

[The prepared statement of Dr. Hollinshead appears in the appendix.]

The CHAIRMAN. Mr. White, in your recommendations for your National Association of Children's Hospitals, one of them was that we continue efforts to expand Medicaid eligibility for children by mandating that eligibility for pregnant women and infants living on incomes below the Federal poverty level.

We put that in the bill yesterday on catastrophic illness. That is done.

Mr. WHITE. Thank you, Senator.

The CHAIRMAN. The other one you recommended was to direct States with fixed day and payment limits on Medicaid, which jeopardize poor children's access to health care, to make exceptions in case of medical necessity for infants receiving inpatient care in a disproportionate share of hospitals. We put that in the bill on catastrophic illness yesterday.

Mr. WHITE. Thank you, Senator. Gee, that is great.

The CHAIRMAN. Do you have anything else on the list?

(Laughter)

The CHAIRMAN. Mr. Halamandaris, when you talk about the emotional stress on the family, that is well understood. I know from personal experience that, when you have that child in the hospital and you have the father staying there 12 hours and then the mother is staying there the other 12 hours, and that goes on for almost a year, they just pass each other on the way to the hospital.

Mr. HALAMANDARIS. Right.

The CHAIRMAN. And what it does to a family is it wreaks some untold damage; and what we can do to try to soften it, we have to do. When you talked about Hubert Humphrey's speech on children living on the edge, of course he was addressing the concern of his Downs syndrome grandchild at that time.

When we talk about chronically ill children and the families and what they have to do in the way of trying to get medical help, social services, and other kinds of support services, what I have done is ask the General Accounting Office to conduct a study to see what can be done to be able to try to get that information at one central point, to see what communities are doing to try to accomplish that.

What do you think the role should be of maternal and child health programs in providing a coordination of those kinds of services? Do you think there is a role there?

Mr. HALAMANDARIS. I think it is essential, as you pointed out in your opening statement. We have a system now that is fragmented. We probably shouldn't even call it a system. So many young children fail between the cracks; and as you pointed out, the stress on families is enormous.

Someone has to take that leadership role, and I think this is the entity to do it.

The CHAIRMAN. I am concerned about the collection of the data so that we can make better judgments and better decisions on these matters.

For example, States have an interest in learning about the successful approaches taken by other States. That is one of the things we have done on the welfare bill that we have now; it is a culmination—a gleaning—of information of various projects done by governors around the United States.

The Federal Government can certainly use the comprehensive information the State agencies are in a position to collect. How could we at the Federal level improve our collection and analysis of information on maternal and child health reported to us by the States? How could this be of help to you? What can we do to further that?

Mr. HALAMANDARIS. Mr. Chairman, I think there are two major moves that are needed. As I am sure you are well aware, the pendulum has swung far in the last few years away from mandates and requirements and highly specific direction from the Federal level to the States.

I think in the process we have lost two things that really are needed at the national level. One is a support and concern for consistently collected data promptly turned around and provided, not only to you as national decision makers, but to us in each State; and that extends far beyond specific program reporting. That is the national data base on children's health itself and needs sprucing up.

Second, the State programs, as you have heard, are endorsing a stronger and more specific required set of basic reporting data items and a schedule and an aggregation of those items into an annual national report that would include comparisons among all the States.

However much we are concerned with this issue, we have recognized that 50 independent entities have a great difficulty keeping an integrated system together without that knitting together at the core; and we strongly suggest that the Bureau of Maternal and Child Health should be given not only the authority but the resources to move rapidly in that direction.

The CHAIRMAN. Dr. Swanson, how effective are the set-asides for special purposes in the Maternal and Child Health Block Grants? Should we be doing more earmarking in that sort of a situation or not?

I defer to any one of you who wants to answer.

Dr. SWANSON. I think the set-asides have had a strong role in providing the study of some of the methodologies of service delivery and in providing trained personnel in these areas to complement the maternal and child health programs.

As new areas of care coordination come forward as an issue that needs defining and methods of measuring what standards of what good care coordination is, there should be money in a set-aside to allow for that kind of study, which would get at some of this problem of 50 different States providing 50 different kinds of care.

I think some definition and standard setting of what good care coordination is could well come from use of the set-aside monies through special projects and university affiliated programs.

The CHAIRMAN. We have a limitation on questioning time, too, because of the number of panels we have this morning; and my time has expired. On the arrival list, the sequence is Senators Rockefeller, Durenberger, Chafee, Daschle, and Wallop. Senator Rockefeller?

OPENING STATEMENT OF HON. JOHN D. ROCKEFELLER IV, A U.S. SENATOR FROM WEST VIRGINIA

Senator ROCKEFELLER. Thank you, Mr. Chairman. The Katie Beckett individual waivers, as I understand it, are being phased out. So, what we have now is the 2176 waiver program, and an estimated 2,300 to 17,000 technology-dependent children with only 938 technology dependent children being covered by 2176 waivers.

That is obviously a shocking figure, but what is even more amazing to me is that in West Virginia there are only two children who receive services through the Katie Beckett waiver, and no applications for the section 2176 waivers.

What is probably at work? Those are highly improbable numbers, and therefore, there must be some extraordinary deficiency. Any of you?

Mr. HALAMANDARIS. Senator, what I can tell you is what I have heard from the parents who are seeking these waivers in Texas. What they tell me is that the procedure is complex; it is time consuming. And the real tragedy that I heard the other day when this was discussed was that one parent had been seeking the waiver for two years; and when the waiver was finally granted, the child had died—had died six months prior to that.

Now, I can't speak exactly to the data that you give from West Virginia that says only two applications have been made because that seems to fly in the face of what I have said; but I can tell you that in Texas what I have heard from the parents is that it is tough to get, and it is a long and a protracted process.

I would concur with what my associate said, that if you can do it outside of the hospital, you can do it cheaper; and the technology is definitely heading in that direction.

So, as a hospital administrator, I would support the parents in that process, and we have a parent support group at the hospital which seeks to have these children placed outside as quickly as possible.

Senator ROCKEFELLER. Are there other thoughts? I mean, even if the bureaucracy and the red tape is extraordinary, and I don't know how many technology-dependent children there are in West Virginia; but I know that there must be more than two. I know that those parents are extraordinarily frightened, caring, determined, in some cases probably helpless, and in some cases possibly split. But surely the fear of red tape wouldn't preclude parents from persisting?

Mr. HALAMANDARIS. Senator, I have a comment, if I may. What we find is that when, as in your State, a State makes it particularly difficult for families to qualify for this care, and what they are inclined to do is move. The State of Pennsylvania has a very generous waiver program.

So, what families are doing in your State is moving across the State line——

Senator ROCKEFELLER. They are just literally picking up and moving?

Mr. HALAMANDARIS. That is right.

Senator ROCKEFELLER. Tell me more about that. Are we unique in that? Do you find that particularly in poor States in general or what?

Mr. HALAMANDARIS. No, sir.

Senator ROCKEFELLER. We have been having a little trouble with Medicaid payments generally.

Mr. HALAMANDARIS. I think the majority of the States have not really implemented the 2176 waiver program the way that Congress intended, and part of it is the pressure on Medicaid in general—the dollars are scarce—and it forces families to move. We have heard of families that have moved to four or five States in order to get coverage. You know, it is unfortunate and it is tragic; but that is what is happening now.

Senator ROCKEFELLER. A little bit like people trying to go to States where they can find jobs—just going from State to State to try to find a job. In this case, they are trying to find a State that will help them.

Mr. HALAMANDARIS. No question. Yes, sir.

Senator ROCKEFELLER. That is extraordinary. You mentioned, Dr. Swanson, in your testimony about the problem of preparation of personnel. I am a passionate advocate of home health care. But the question of preparation of personnel is obviously very, very key in terms of home health care, especially in rural States like West Virginia.

How does that work out when homes are far from a hospital? You want to be able to let a technology-dependent child go home, but how do you prepare the parents? Preparation of personnel, I would think, would be a very sophisticated process in this case.

What are the prospects of home health care for technology-dependent children in very rural States like my own?

Mr. HALAMANDARIS. If I can respond, Senator, I think that almost any child, even those with the most intensive medical and nursing needs, can be cared for at home, number one.

Number two, the families——

Senator ROCKEFELLER. But why do you say that?

Mr. HALAMANDARIS. From personal experience, the respirator-dependent children are perhaps the most fragile; and the Surgeon

General of the United States, Everett Koop, said if we can move those kids at home, we can move any of them at home.

So, it is a matter of training of the families themselves and of personnel; both physicians and nurses have to be trained in the care of these fragile dependent children.

Senator ROCKEFELLER. And these families can be trained?

Mr. HALAMANDARIS. Yes, sir. It is very important that that be done.

Senator ROCKEFELLER. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you. Senator Durenberger?

OPENING STATEMENT OF HON. DAVE DURENBERGER, A U.S. SENATOR FROM MINNESOTA

Senator DURENBERGER. Mr. Chairman, thank you. I do have a prepared statement that I would like to have included in the record.

The CHAIRMAN. Without objection.

Senator DURENBERGER. Mr. Chairman, I rode over on the subway this morning with our colleague, Senator Hollings, and he was surrounded by six or seven people on the way to do his amendment or something; and I sort of kidded him about the fact that he looks like a governor because we are sort of used to seeing governors—and he was a governor about 25 or 30 years ago or something like that—going around surrounded by an entourage while we wander about without aides and all that sort of thing.

(Laughter)

Senator DURENBERGER. But it sort of brings up the issue of how much power, authority, and capability do all of these aides represent standing around these governors? And it gets us to one of the points here that I think is going to come up repeatedly this morning.

I think Dr. Healy from Iowa, when he gets up here, is going to say about the system: The present system by offering better health care coverage to a child based on where he or she lives is inequitable and discriminatory. I think that is one of the things that has been bothering all of us about what has happened in the last 30 years since Fritz Hollings was a governor in South Carolina.

I mean, if you just look at the numerology of the Social Security Act, in the early titles, V and VI are about kids; the late titles, XVIII, XIX, and XX, are all about the elderly. And I think in a sense we celebrate that, that we finally have got to stop povertizing the elderly in America.

I mean, we finally have a system where older people can be proud of the fact that they have earned their retirement and they don't have to retire to poverty, and they don't have to be dependent on their kids and all that sort of thing.

And it is nice to celebrate that; but our problem, I think, reflected today in the hearing that the chairman has called is that we have forgotten about everything else.

In effect, what we have done is we have pointed the elderly in the direction of the national Government; we have said now the national Government is going to take care of you. You have Social Security; you have Jimmy Roosevelt lobbies; you have Claude

Pepper; you have all of these great things going for you—all out in Washington, D.C.

We are pointing the other direction; we are pointing back at these governors who are strapped still with the responsibilities of the local governments to do all of these things. They have all of these problems and this relative disparity in their tax base; and we are saying you take care of the kids. You educate them; you provide for them; and we will have these block grants or something like that that you can kind of spread around.

I think Dr. Hollinshead shares with me the frustration of those of us on the Infant Mortality Commission, which is the only kind of national thing we have got going now, other than Lloyd Bentsen——

[Laughter.]

Senator DURENBERGER. Trying to maybe point us in the direction of taking on some national responsibility for all of us. I mean, it isn't to the exclusion of the governors; it isn't to the exclusion of State and local entities. But maybe the social insurance program in this country in its titles ought to say there is a national responsibility to take advantage of some of these opportunities to resolve [illegible] problem, not based on where you live, but because you are a [illegible].

Does anybody disagree with that on this panel?

[No response.]

Senator DURENBERGER. Let me make one other observation, which is again about what we did yesterday—again under the leadership of our Chairman—and everybody here participated in that [illegible]. That is, we did in 1988 what we should have done in 1965; [illegible] into the Nation's social insurance program.

[illegible] people who are elderly or disabled are going to have what [illegible] a need, and that is protection against financial catastrophe. [illegible] the first time we didn't identify it in medical terms, [illegible] there is a debate going on as to whether we did acute [illegible] long-term care; I don't tend to focus on that.

I [illegible] focus on the fact that what we did yesterday was a first, [illegible] step in saying we are going to measure catastrophe [illegible] terms and in the social insurance system we are going [illegible] a kind of uncontested variety in the subsidies for people who fall in this category of a financial catastrophe.

Until then, we are going to sit back and hopefully watch the insurance system out there, and maybe these State programs, react better now to providing people their needs because catastrophe is there; but that is just the beginning.

As I understand it—and I think is reflected in some of your statements—the next part of catastrophic is not just going on in more so-called "old people" or elderly stuff, it is looking at insurance programs. And everybody on this committee knows that.

All of these employer-based insurance programs don't require catastrophic. It is the cheapest thing to put in there, but there is no requirement.

We have been struggling since I got here to figure out how we can do that. How can we mandate catastrophic? Don't mandate anything else; just mandate catastrophic. And if we did that, I suppose you would say to us: That would be a big step in the right direction because that unexpected cerebral palsy or spinabifeda kid or ventilator-dependent kid or whatever would be covered by some broad-based insurance. Do you agree with that?

Mr. WHITE. Sure.

Senator DURENBERGER. Thank you, Mr. Chairman.

The CHAIRMAN. Senator Chafee?

Senator CHAFEE. Thank you very much, Mr. Chairman. I have a statement I would like to put in the record.

The CHAIRMAN. Without objection.

Senator CHAFEE. Thank you. There are a couple of points I would like to make. I just think that we want to harken back to the hearing we had last Tuesday, which was on preventive medicine for the children, and I think that we don't want to lose sight of that, and obviously they are not antithetical, caring for children and preventing the onslaught of these sicknesses and illnesses that children can fall victim to.

So, I am extremely interested in that part of it, and there is no question but what—as you have all mentioned—there is a bias in our system now toward hospital or institutional care as opposed to the home care; and that is the thrust that we want to get away from.

And that is why I have been so vigorous in supporting a 1673; I think you mentioned that, Dr. Hollinshead, which is the Home and Community-Based Services Act, which would take care of the problem Senator Rockefeller mentioned of the 2176 waivers, the requirement of the waivers.

We wouldn't have to have these waivers under our legislation, and I hope we will have an opportunity before this year is over to consider that legislation here in the committee.

I would like to ask you a question. Last Tuesday, we had some horror stories on the Medicaid applications. It sounded like somebody was trying to get clearance to work on nuclear weapons, and there were indications that some of these applications were 20 to 40 pages long.

Is that an exception, Dr. Hollinshead? Take in our State, how complicated is it to fill out a Medicaid application?

Dr. HOLLINSHEAD. That is not an exception. There are a variety of reasons for it, but as Governor Reilly has pointed out and several others, State after State after State has a so-called common application form that serves all welfare programs, but is usually absolutely required to get into Medicaid.

It is a formidable document, often much larger than the corporate income tax return, as he is fond of pointing out.

Senator CHAFEE. Do the rest of you concur with that?

Mr. WHITE. Yes, sir.

Senator CHAFEE. That is unfortunate. Of course, that is enough to turn anybody off from applying. We also had testimony that only 50 percent—and the 50 percent was high—of Medicaid eligible people take advantage of Medicaid, or that it is accessible to them; maybe that is a better way of phrasing it. Do your statistics bear that out?

In our State, that would seem hard to believe, Doctor, with it being so congested, if you would, and everything being fairly close.

I can see it in the great, wide-open space States; but is that true in our State?

Dr. **Hollinshead**. I am not sure how solid our estimates of potentially Medicaid eligible people nationally are. A higher proportion are enrolled in Rhode Island; I suspect there are some States where the proportion is actually lower.

And of course, the threshold for Medicaid eligibility is far from consistent from State to State. That is an issue that I gather is being addressed this year.

Senator **Chafee**. We addressed it yesterday in the care for pregnant women. What do you say to that, Mr. White?

Mr. **White**. I want to give you a different slant on it, Senator. As an administrator of a hospital, which depends heavily on Medicaid, we frankly couldn't afford to have any potentially medicaid eligible children not get on the program; and we can't leave it to their own discretion or the parents' discretion to get on.

So, we employ special people in the hospital to take the parents through the application process and make sure that they get on and follow up. There is a whole series of hurdles once you put the data in that you have to clear in order to get on, and then you don't stay on all the time. You can go off if certain things don't happen.

So, our people do this, and they do it pretty well; but that is an added expense. And it is frankly preservation for us. With a 50 percent Medicaid level, if we didn't get what is paid, we would be in worse shape than we are now.

Senator **Chafee**. Are any of you familiar with the 1537, which is the Catastrophic Health Care Program that I introduced? I think you mentioned it, didn't you, Dr. Hollinshead?

Dr. **Hollinshead**. Yes.

Senator **Chafee**. Is anybody else familiar with that?

(No response)

Senator **Chafee**. What do you think of it, Dr. Hollinshead? I am lobbing one up to you. Step right up to the plate now——

(Laughter)

Dr. **Hollinshead**. I will be happy to return that serve. I think that the two needs addressed in that bill are very important ones. As you know, the legislation suggests that the uncompensated care for long-stay newborns was a very important issue. That clearly is the case in many States.

There is an attempt to address that very serious issue. It does not extend as far up into the older children as perhaps we should eventually be, but it is a start in that direction.

Second and of most interest obviously to us, the specific inclusion of public responsibility for coordination of care in there, we believe, is absolutely critical to make the system work.

Senator **Chafee**. Let me just say in conclusion, Mr. Chairman, that it seems to me the thrust we should work for: one is to do everything we can to keep all individuals—but now we are addressing children—out of hospitals, out of institutions, provide for equipment for them at home, and have respite care to give the parents some relief.

And I said it was Dr. Hollinshead or Mr. White who said some training for the parents is essential so they can know how to handle this equipment and step in there and take care of these children as they want to do at home. There is no question but that the children do far better at home than they do in an institution.

Mr. White. I would agree with you, Senator. I would comment, though, that with these chronic kids, from time to time even though they are home, they have to return to the hospital for a checkup, for adjustments—the doctors call it a "tune-up"—but it is necessary, and it isn't lengthy, and it allows them to go back into the home setting for lengthy periods of time.

Senator Chafee. All right. Thank you.

The Chairman. Thank you very much. Senator Daschle?

OPENING STATEMENT OF HON. TOM DASCHLE, A U.S. SENATOR FROM SOUTH DAKOTA

Senator Daschle. Thank you, Mr. Chairman. Mr. White, I would like to follow up on something you just addressed to Senator Chafee with regard to the process you use to deal with Medicaid eligibility.

You said you have people who process these applications, which is commendable, but it is also a practical service from your point of view. Obviously, it is more than just an unwillingness to fill out the forms that keep a lot of people from being eligible for Medicaid.

What do you do? What happens in those cases where you find eligibility is a problem? And in what percent of cases do you find people are not eligible?

Mr. White. Eligibility is a problem. Where it is most obvious is when we have a child in the hospital for a serious, chronic problem. The child stays in for a long period of time and goes through the limited eligibility that Texas has.

There is nothing we can do under those circumstances. When we accept a child into the hospital, we accept for the care during that stay and quite often for repeat care if that child needs it.

Now, in the case where we have a child who has no Medicaid eligibility but is admitted into the hospital—let's say an emergency situation where the child enters our emergency room, needing care right now—and we provide the care in the hospital, but the child isn't eligible, we will eat that bill.

And if that child needs follow-up care, we really have two choices there. We can attempt to find follow-up care in another institution which has a different source of funds, for example, a county hospital.

You can do that where the kind of problem that the child has can be managed at that particular county hospital. Sometimes they can, and sometimes they can't. Some are very good in pediatric care; others are not.

If the problem that the child has is not particularly well managed in another setting, or is a particular specialty of the children's hospital, we will continue to have that child come in. We will continue to eat that bill. We will fund that bill through our other sources of funds continuously, and that can go on year after year.

Senator Daschle. Let me ask you the second part of that question. I am trying to get a sense of how big a caseload problem you have to deal with. What would be your estimate of the caseload wherein that becomes a problem?

Mr. WHITE. All right. I will give it to you in dollars and see if that can give you the ratios you are looking for.

We have total charges of about $35 million annually. $12 million of that is not reimbursed. $9 of that $12 is not reimbursed because of Medicaid problems. $3 of that $9 million comes out of this lack of eligibility issue that you are talking about; the other six is because the DRGs don't pay what the costs are.

Senator DASCHLE. About 10 percent in your case. Would any of you care to indicate whether that varies significantly from your experience? Can anybody else on the panel speak to that?

Dr. HOLLINSHEAD. I would estimate to make a hard estimate in numerical terms, although I think we could talk to the range of that. Again, State to State variation, not only in eligibility and benefit kinds of levels, but also in the stickiness, unfriendliness of the process will govern that proportion a good deal.

And in States with perhaps more generous Medicaid programs, they may have other barriers that lead to a substantial gap.

Dr. SWANSON. In Texas, at Parkland Hospital, which has about 15,000 births, their estimated reimbursement rate for Medicaid for charges in recent years is about eight percent overall of what they charge. This is for neonatal intensive care.

And there are great barriers to getting those babies and mothers on Medicaid for neonatal intensive care—the premature babies—and their return rate is extraordinarily low from the Medicaid system.

Senator DASCHLE. And in those cases where ineligibility becomes a major problem, do you find that most hospitals are willing to "eat the costs?" Or do you find cases where Medicaid patients, especially children, are turned away? Does that happen?

Mr. WHITE. Each hospital in our community has its own practices. They set their own limits on what they are willing to provide in levels of community service. Some are more so than others.

In our case, outside the county hospital, we are the most generous. Those hospitals know that; and so, they will refer to us when they exceed their own limits.

Senator DASCHLE. I guess my time is up, but I was just wondering whether there are experiences that you might be able to elaborate a little bit on where hospitals find themselves in a position of forcing children to look elsewhere for health care.

Maybe you can't provide that information to the committee, but that would be interesting to know.

The CHAIRMAN. I get the impression from what you have just said that some of these others do just that—send them over to you?

Mr. WHITE. Yes, that is true. It doesn't appear that way. The way it usually comes out is "we have no beds." "We are all filled up; we don't have the staffing level."

If you look at it a little closer, though, you understand that they have reached their own limits; and they would prefer somebody else takes on the burden.

Senator DASCHLE. There is a little difference though in "referring," if you can use that term generously, a patient to a hospital that you know will take the patient and to tell a child at the door that "we just don't have room for you, and we can't tell you where to go." That is what I was trying to get at; that is a commendable thing, and you must have an excellent rapport with your other hospitals if you are willing to do that.

Mr. HALAMANDARIS. One final comment, Senator. What happens is the county hospitals or the public hospitals become the great dumping grounds. And the people who can't be taken any place else wind up on the doorstep of the local county facility; and they simply must bear the burden.

That is the institute of last resort.

The CHAIRMAN. Thank you very much, Gentlemen. We appreciate your contribution this morning. It has been very helpful. Thank you.

The next panel will be composed of Dr. Alfred Healy, Professor, Department of Pediatrics, Division of Special Education, University of Iowa; Dr. Billy Arant, Director, Division of Nephrology, Department of Pediatrics, University of Texas; and Dr. William Neal, Professor and Chairman, Department of Pediatrics, West Virginia University. Would you please come forward?

Dr. Healy, if you would proceed, please?

STATEMENT OF ALFRED HEALY, M.D., PROFESSOR, DEPARTMENT OF PEDIATRICS AND DIVISION OF SPECIAL EDUCATION, UNIVERSITY OF IOWA HOSPITALS AND CLINICS; TESTIFYING ON BEHALF OF THE AMERICAN ACADEMY OF PEDIATRICS, AND THE CONSORTIUM FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES, TASK FORCES ON CHILDREN AND HEALTH, IOWA CITY, IA

Dr. HEALY. Thank you, Mr. Chairman. I am here today on behalf of the American Academy of Pediatrics, the American Medical Schools Pediatric Department Chairmen, the Consortium for Citizens with Developmental Disabilities, Task Forces on Children and Health, the American Pediatric Society, and the Society for Pediatric Research.

Mr. Chairman, we want to commend you and your committee for your tireless advocacy on behalf of the health care needs of children in this country. Nevertheless, despite your best efforts and those of your colleagues, there remains a significant unfulfilled agenda regarding the health needs of children in this country.

This is particularly true for those children with chronic illness and disabilities. Their health needs are usually multiple, recur over time, and serve as barriers to their eventual independence, productivity, and integration into community life.

Financing of health care for children with such special needs is as complex as the health problems themselves. Developmental disabilities and chronic illness are growing problems among children and adolescents, and their health care utilization and expenditures have increased accordingly.

In spite of much well documented information, major national health financing programs exist only for very low income persons—Medicaid—and for the elderly—Medicare. There is no comparable national program or commitment to the health care of children, let alone children with special health care needs.

Recent studies suggest two to four percent of all United States children currently experience severe, chronic health conditions or disabilities and that, during the last two decades, the number has doubled. In addition, 80 percent of children with the most common, severe, chronic health impairments now live to adulthood.

Children with developmental disabilities and chronic illness have common interrelated psychosocial, medical, and educational needs, which go beyond those experienced by healthy children or those with acute illness. They require more frequent and high intensity use of specialty and primary care medical services, as well as the services of a variety of outpatient hospital and home health care personnel.

Numerous studies have documented that coordination of care improves the quality of that care, reduces duplication of effort, and produces cost-effective use of health care resources. All children with chronic illness and disabilities and their families should have access to such unified, family-focused, coordinated care.

Mr. Chairman, we would like to make the following specific recommendations. They relate to the Maternal and Child Health Block Grant Program and the Medicaid Program.

The major point I desire to make is the need for a fresh look at both programs. We as a Nation are in a desperate need of developing a unified system of health care for all children, including those with acute and chronic health care needs.

First, regarding the Maternal and Child Health Program, we recognize the critical need to improve coordination of health care services. Therefore, we would advocate for the development of an increased and expanded coordinating and planning capacity, perhaps through a State advisory council, while at the same time advocating for continuation and expansion of the precious little funding that is currently available through that program for direct health care services to this population of children.

It is our position that children with chronic health impairments and disabilities currently receive such relatively minimal funding that they deserve to have their cake and eat it, too.

Second, you have our written testimony documenting specific recommendations to improve the Medicaid Program. Overall, we believe that the existing State by State variation has made the program ineffective and essentially nonexistent for many children.

We recommend mandatory increased and improved coverage in benefits for specific cohorts of pregnant women, including children with chronic illness and disabilities, such as those bills proposed by Senator Durenberger and Senator Chafee.

We also encourage efforts to remove the barriers that currently exist to access Medicaid services, such as that which was recently introduced in my State of Iowa, where access to consultative medical care has just been restricted to one visit per year per child for any illness, including chronic illness and disability.

We also encourage efforts for the program to provide appropriate compensation for services, as others have mentioned this morning.

We thank you, Mr. Chairman, for the opportunity to present our concerns and recommendations.

The CHAIRMAN. Thank you.

[The prepared statement of Dr. Healy appears in the appendix.]

The CHAIRMAN. Dr. Arant?

STATEMENT OF BILLY S. ARANT, JR., M.D., PROFESSOR OF PEDIATRICS, AND DIRECTOR, DIVISION OF NEPHROLOGY, DEPARTMENT OF PEDIATRICS, UNIVERSITY OF TEXAS, SOUTHWESTERN MEDICAL CENTER; TESTIFYING ON BEHALF OF THE AMERICAN SOCIETY OF PEDIATRIC NEPHROLOGY, DALLAS, TX

Dr. ARANT. Mr. Chairman and members of the committee, my name is Billy S. Arant, Jr. I am a Professor of Pediatrics and Director of the Division of Pediatric Nephrology, University of Texas, Southwestern Medical Center in Dallas, Texas. I am also Secretary-Treasurer of the American Society of Pediatric Nephrology, an organization of 325 members which I represent and speak for today.

Mr. Chairman, I appreciate your efforts in the past, and I am proud that you are my Senator and have taken the initiative in calling these hearings with a commitment to solving this problem. I would be much happier if we were meeting here to celebrate the solution to the problem, rather than the initiation; but perhaps we can reconvene at a later time.

The United States currently faces a crisis of major proportions in providing health care to children with chronic illness due to kidney disease. The problem is manifold.

First, the financial impact of chronic renal disease on the child and his or her family can be devastating. When faced with a prenatal finding of abnormal kidneys in the unborn child, and information about the cost of providing medical care to the child following birth, parents are being forced to consider measures to intervene in the pregnancy, even when effective treatment is available, but unaffordable.

Second, as advances in medical knowledge and technology have saved the lives of neonates, infants, children, and adolescents who previously would have died, the number of children requiring medical care for kidney-related disorders--some actually caused by the successful treatment of premature birth, treatment of cancer, and the treatment of heart disease—has increased dramatically.

Third, there are too few physicians trained to provide the specialized care required for infants and children with kidney disease. In some regions of the country—ten States in fact—there is no such care available at all.

Often, costly medical and surgical care of a child with kidney disease occurs before the full earning potential of the parents has been attained. Children born with or who develop renal disease after birth are usually excluded for as long as 90 days or denied insurance benefits all together because of so-called "preexisting illness."

In view of the enormous cost of neonatal intensive care, this results in an unacceptable burden for almost all affected families. The expensive treatment of children with kidney disease is usually not available in public hospitals.

With an increasing number of patients needing medical care but with fewer possibilities for reimbursement, patients and their families are soon rendered indigent by the cost of treating kidney disease of just one child; and it is not unusual for two or more children in the same family to have the same kind of kidney disease.

Whereas Title V or comparative State-supported programs cover urologic, neurologic, cardiologic, and oncologic conditions, most kidney conditions are excluded prior to the time complete kidney failure occurs, which could be either months or as long as 12 or 15 years.

The costs of providing medicines, nutrition, psychiatric and psychological services, educational resources, and nursing are not provided by private, governmental, or third party health cost providers.

Middle income families may have enough resources to preclude eligibility for Government-funded medical care for their children with renal diseases. Although adequate funds are available for children with end-stage renal disease through Medicare, the majority of infants and children with congenital or inherited renal disorders have renal insufficiency that is debilitating and expensive, but not funded until the criterion of end-stage renal disease is met.

Even for children with kidney failure, the fraction not covered by Medicare, as well as the cost of medications and transportation to a tertiary care center, result in overwhelming debts. Private foundations have not filled the gap.

It is essential that funds be made available to those families with [illegible] resources.

We recommend several approaches as a solution to this problem [illegible] children with kidney disease.

[illegible] require third party carriers providing family health [illegible] to ensure the unborn or newly born child from birth, [illegible] of condition. That is in place in some States, but it is not [illegible] in all States.

[illegible] second would be to provide Federal or State funds like Medicaid for children with kidney disease at a time when a decreasing [illegible] function does not yet require dialysis or transplantation [illegible] then covered by Medicare in part, but when the costs of [illegible] for the child are still great in preventing the kidney [illegible] through diet and medication.

Finally, we would suggest that there be a restructuring of [illegible] reimbursement by Medicare to hospitals and physicians for the treatment of end-stage renal disease in infants and children. There is a misconception that Medicare covers the cost for end-stage care for children with kidney disease, like it does in the adults.

The original guidelines and rates for reimbursement for Medicare were based upon the costs of caring for adults 15 years ago. Those have not been updated; if anything, they have been reduced. Now that we treat children with dialysis, it is not possible to provide that care at cost reimbursement for adults, either in the hospital or for outpatient management. Such care given a newborn infant might require up to 30 percent of the time of one highly skillful physician for which there is little possibility for reimbursement either to the physician or to the hospital.

So, we would suggest a restructuring of the Medicare reimbursement rates for the prolonged time and additional expertise that is different in taking care of kidney failure in children than in adults. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Dr. Arant.

[The prepared statement of Dr. Arant appears in the appendix.]

The CHAIRMAN. Dr. Neal?

STATEMENT OF WILLIAM A. NEAL, M.D., PROFESSOR AND CHAIRMAN, DEPARTMENT OF PEDIATRICS, WEST VIRGINIA UNIVERSITY, SCHOOL OF MEDICINE, MORGANTOWN, WV

Dr. NEAL. Mr. Chairman, it is a privilege to speak with you today about the health and well-being of the children of this Nation. I represent the national Perinatal Association, which is a provider and consumer organization dedicated to this goal by fostering optimal care, education, research, and ordering of national priorities.

As a practicing pediatric cardiologist and Professor and Chairman of the Department of Pediatrics at West Virginia University, I am honored to also represent my native State and its land grant institution of higher education.

I initially developed my interest from a rather narrow focus, my interest in maternal and child health issues and perinatal issues. As a young faculty member having recently completed graduate training at the University of Minnesota, I was apprehensive about returning to West Virginia because of the lack of newborn intensive care services, both at the university hospital—this was in [illegible] throughout the rest of the State; and it was not possible to [illegible] state-of-the-art modern-day pediatric cardiology without [illegible] newborn intensive care services.

[illegible] of the department at that time rendered a challenge to [illegible] these services if I thought that they were so necessary, and that is how I got into developing my interest in both [illegible]ally—simply to develop it so we could practice [illegible] now, again recognizing that the problem was much [illegible].

[illegible] the regional medical program, which was in existence [illegible] the funds for equipment and was turned down. [illegible] came back to me and said we can provide you [illegible] planning grant; and so, we received a $30,000 planning grant, which allowed the development of the perinatal committee which was comprised of both providers and consumers throughout the State.

This committee turned out to be delightfully successful in terms of planning an effective regionalized system of neonatal care for the State of West Virginia. That led to an interest in regional and then national perinatal issues from that.

This program in West Virginia was successful during the late 1970s—during that decade—in that the white infant mortality rate in West Virginia was the worst in the Nation, and the overall infant mortality rate plummeted more rapidly during that decade than any State in the Union to slightly below the national average.

So, I think that certainly was an indication that effective programming in a State can accomplish a goal.

The main message of my written testimony was to say that neither our State nor any other State can make further progress in terms of infant mortality without tremendous efforts in terms of trying to see that all women in this country receive prenatal care. Nothing further is going to happen in terms of reducing mortality until that really happens.

So, I think, as you are well aware, that is a challenge for us in the future.

I might simply digress from the written testimony then to point out that, as a child health advocate in my State and as an administrator of a pediatric department, it is a constant uphill battle to try and receive funds so that programs can be developed.

Senator Rockefeller, when he was governor of our State, blessed us with divestiture of the university hospital from State control which allowed us to build a new state-of-the-art facility. However, one of the problems that occurred, at least during the planning phase, was the administration said we would have to cut our neonatal intensive care program by at least one-third, simply because it is cost-ineffective; the hospital loses money on that program.

Fortunately, that did not occur; but trying to develop child development programs within the State, trying to develop other services, both from an academic and from a purely service point of view, is constantly an uphill battle for children. And that should not be the case.

My recommendation simply, as others have made, is that this needs more Federal regulation. The Medicaid Program is too uneven from State to State, and it needs to be evened out. We have really 50 different Medicaid systems, and I think it should be one system essentially that advocates for all children in this country, despite various problems of economies and so forth from State to State.

Thank you, Mr. Chairman.

[The prepared statement of Dr. Neal appears in the appendix.]

The CHAIRMAN. Thank you, Dr. Neal.

What you are saying Dr. Neal, as was said in so many statements yesterday, is how important it is to have the prenatal health care and how often we can avoid some devastating illnesses later on. What can we do to improve the outreach program to pregnant women?

Dr. NEAL. I think, first of all, we talk about the need for access to prenatal care, namely that all women must have the ability—without regard to finances and so forth—to receive prenatal care. Uniform access, however, I think is only part of the problem.

You also have to see that once all women can receive it—again without regard to ability to pay—that they take advantage of it and that they do so early in the pregnancy.

The CHAIRMAN. What can we do from the Federal side to try to coordinate the services?

Dr. NEAL. I think from the Federal side what needs to be done is to mandate to the States that all women be eligible.

The CHAIRMAN. I was interested, Dr. Arant, in your statement about the potential that you have for childhood kidney disease strategies that could prevent serious problems in adults later on.

I assume we must have other potentials like that other than just the question of kidney disease. Would you care to elaborate on that? It looks like you have some enormous payoffs.

Dr. ARANT. There are obviously parallels in other conditions, some documented, others suspected, such as the role of physical fitness, the role of diet, and other things affecting morbidity in adult life; but specifically, we are talking about the large expenses of Medicare—the $3 billion a year—for treating adults with end-stage renal disease.

Eighty percent of those people's kidney diseases started in childhood. There is absolutely no Federal program in place to intervene in those diseases during childhood to prevent kidney failure or its consequences.

Diabetes, for instance, accounts for 30 percent of those adult patients on dialysis. There are great efforts for identifying and treating the causes of blindness and for many other complications of the diabetes, but not for kidney failure in children. All programs start in adolescents or adults, not in the child when the disease begins; and it is often too late.

There are other such diseases, but there is no focus on prevention and early management to reduce this very, very costly treatment in the adult.

Dr. HEALY. In addition to those which he just referred to concerning the chronically ill child, there are many cohorts of children and young adults with developmental disabilities—physical kinds of conditions—mental retardation; learning disabilities—that can profit greatly from early intervention, especially relating to the time of infancy when the parents and families are just becoming associated and knowledgeable of the problem.

The CHAIRMAN. There is no question about that. I just spent some time in a Down's syndrome school in San Antonio and seeing what they were able to do with those very young children, where they wouldn't be spending the rest of their lives sitting in front of a TV set, but actually could have some degree of productivity.

We have such a limited amount of time, I will defer the rest of my questions. Senator Rockefeller?

Senator ROCKEFELLER. Thank you, Mr. Chairman. I have an opening statement I would like to put in the record, if I might.

The CHAIRMAN. Without objection, that will be done.

Senator ROCKEFELLER. Dr. Neal, I am obviously very glad to see you, and we will be meeting again this afternoon. We have in the State a transport system that gets sick infants and high-risk mothers to your hospital for medical care.

Now, some of these, of course, are premature infants and have to stay in the intensive care unit; they may be there three to six months. What interests me is what happens when a child of that age and condition is hospitalized for six months, when the family of that child is poor, when the family of that child lives far away.

Are they able to visit the baby? Are they sustained in some way or sustaining to the child or to the medical team in some way? I would think it would be very, very difficult for families. You don't stay in the Morgantown area at a motel without paying a lot. Could you reflect on that a bit? And tell us a little bit about its effects on your efforts.

Dr. NEAL. Yes, sir. It is certainly a very serious, depressing situation because, for example, certain conditions, as you well know, are covered by handicapped children's services; and families can receive some funds for motel and so forth during the acute phase of any illness.

However, prematurity—the problem of prematurity—which is the reason for which most of these infants are referred and brought to the hospital, is not covered under handicapped children's service simply because the State does not have sufficient money to cover it.

Therefore, the social service of being given funds for meals and for lodging are simply not available to those parents. Consequently, what we see in our present facility, which is really inadequate in terms of a place for parents to stay in the rooms and so forth, is parents having to literally sit and sleep all night in the main lobby, oftentimes sit in the hallways, laying down really in any place that they might be able to find, which I think is degrading to any person.

Fortunately, in the new university hospital facility, recognizing that problem, there is in every patient's room a bed which is available for the parents to sleep in. We are also doing what so many other hospitals have done to help in this situation, namely develop a Ronald McDonald House through community efforts to allow parents to stay.

Senator ROCKEFELLER. Is where a child comes from, where he is flown in from, or brought to the hospital from—if it is far away or close—does that in any way affect your discharge decision?

Dr. NEAL. It does in one respect. Our whole strategy is to see that any baby or child that needs hospitalization has this done as close to home as possible, and that is what regionalization is all about.

Another decision that it affects is that, as soon as we feel that it is safe, we back transfer children to hospitals closer to where they live for their continued care. Fortunately, the hospitals in West Virginia oftentimes, despite reimbursement at that point, will nevertheless accept those children or those babies back so that they can stay in the hospital for several more months, possibly for gaining weight—for that reason alone—we will send them to a hospital that is closer to where the parents live.

Parents who live, however, a long distance away and the baby or child must remain in the university hospital, which is very centrally located—very close to the Pennsylvania border—and if they happen to be from the central or southern part of the State, oftentimes simply cannot visit; and that is tragic in and of itself.

Senator ROCKEFELLER. One final question. A point can be made in terms of the neonatal intensive care units that, up to 15 percent of those infants, would not need intensive care if their mothers had received adequate prenatal care. That strikes me, in fact, as a rather low figure.

Dr. NEAL. I think it is low. However, I don't have documentable data to refute the figure; but we recognize that about two-thirds of all high-risk conditions can be recognized prior to birth. And at least one-third of women in West Virginia receive no prenatal care; so, it would seem that if all women were to receive prenatal care and all high-risk conditions were recognized that can be medically treated appropriately, it would in fact reduce the incidence of most prematurity considerably and the conditions resulting from it.

Senator ROCKEFELLER. Mr. Chairman, one really quick question, if I might? He is a real West Virginian. Is there a tendency among some parents in very rural areas to resist intervention during their pregnancy?

Dr. NEAL. I think that is true. It is very subtle, but West Virginians and especially very rural West Virginians are very independent; and that is a good quality in many respects, but it is a bad quality in that they often don't integrate into a society as well as one would hope.

Senator ROCKEFELLER. And some are more reluctant to receive assistance?

Dr. NEAL. Yes, sir. Doctors and health care providers are looked upon as authority figures, and they resent all authority figures, no matter whom they might be.

Senator ROCKEFELLER. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you very much, Senator Rockefeller. Senator Chafee?

Senator CHAFEE. Thank you, Mr. Chairman. Dr. Neal, did you say one-third of all women in West Virginia—expectant mothers—do not receive any prenatal care?

Dr. NEAL. Actually, I should have said do not receive prenatal care during the first trimester.

Senator CHAFEE. Oh, I see.

Dr. NEAL. A lower percentage, but as I recall, somewhere in the neighborhood of 20 percent receive no prenatal care—18 to 20 percent.

Senator CHAFEE. Throughout their pregnancy?

Dr. NEAL. Yes, sir.

Senator CHAFEE. I must say, those are astonishing figures. I think the testimony we have here is really informative; we do know these facts, but to have them come before us once again is extremely disturbing.

In Dr. Healy's testimony, where he says that one percent of all children born in the United States die in their first year—I find that shocking, a statistic like that.

Dr. HEALY. Unfortunately, Senator, it was lower previously; but it is again on the rise.

Senator CHAFEE. And there is a direct correlation between infant mortality and childhood illnesses and handicaps—the two are directly related, aren't they—premature babies and low weight infants? There is a tie between that and the infant mortality.

If the infant mortality is high, then the chances of the children being born having handicaps is high also?

Dr. HEALY. That is correct, Senator.

Senator CHAFEE. And the chances of their being premature is high, and the chances of their being low weight is high also?

Dr. HEALY. That is correct.

Senator CHAFEE. Do you think that there is something in the structure of our society that inevitably is going to make us higher than other nations, comparing us to Sweden or Japan or Switzerland? Is that a fair comparison because of the mobility of our population, the lack of homogeneity in our population?

Inevitably, are we going to have higher statistics? Not that that is any excuse, but I am just curious from a sociological point of view what your observations are.

Dr. **Healy**. That is an extremely complex issue, sir and, obviously, considerably debated among those who are knowledgeable in this country. There are a variety of factors that surround it, including definitions of live-born children and other definitions of care.

I would be hesitant to make a very dogmatic statement whether we have the capacity within this Nation to be absolutely number one in the world; but there is absolutely no question that we can vastly improve our current status and move to a position of leadership as opposed to being one extremely low in the statistics at the present time.

Senator **Chafee**. I agree completely with that, and I just think we have got to make tremendous progress in this country in this particular area. If we make the services available, can we get them to come? What more can we do when the services are available to get the women to come?

And indeed, you mention in your testimony that U.S. girls under 15 years of age are five times more likely to give birth than in other developed countries. So, we have that problem of the teenagers becoming pregnant.

Dr. **Healy**. It is a question, sir, of making our young people aware of the fantastic responsibility they take on in terms of parenthood. We need programs within our schools to better educate our young people regarding the responsibilities of the care of their bodies and their reproductive systems so that they are more aware of the need to enter into this responsibility appropriately and, therefore, the need for very early entry into prenatal care.

The moment a young woman realizes she is pregnant, she must enter into that system.

Senator **Chafee**. I would like to ask the panel a question, and I know my time is getting short. Is there agreement that we need noninstitutional care for children with developmental disabilities?

The whole thrust of our Medicaid system now, with the exception of those who receive waivers, is institutionalization. Do you have any thoughts on that?

Dr. **Healy**. I would respond and say very definitely that we need to move significantly away from institutional care. There are some that would suggest that a small residual of institutional care must remain, but without question, the vast majority of institutional care for the developmentally disabled, as it exists in this country today, must be removed.

Dr. **Neal**. I would agree; and I would only point out, however, I have had one patient of mine who in fact was being deinstitutionalized by State and whom the mother felt that that was not in the best interests of the child. And knowing that entire case and its complexity, I agreed with her.

We were ultimately able to keep the child in, but only with a great deal of effort. So, there are very, very few cases that may be better off institutionalized as opposed to deinstitutionalized.

Senator **Chafee**. Very few that are better off.

Dr. **Neal**. Very few. And the main points, I do agree with you.

Senator CHAFEE. So, the main thrust should be getting them out of institutions and Medicaid paying for them in the residential, foster home, community-based setting?

Dr. NEAL. Absolutely.

Senator CHAFEE. Now, you can say that, Dr. Arant, too, for the record if you would like.

Dr. ARANT. Yes, sir. I agree fully.

Senator CHAFEE. Because we have legislation we have been trying to get through this Congress, which we now have nine cosponsors on this committee, dealing with that very subject. You support it, too, Dr. Healy?

Dr. HEALY. Yes, sir.

Senator CHAFEE. Good.

Senator ROCKEFELLER. Senator Daschle?

Senator DASCHLE. Thank you, Mr. Chairman. I have never had the opportunity to ask a panel of physicians about this infant mortality rate. It is troubling to me. Dr. Healy's answer was that there is a great deal of controversy and complexity to determining really what mortality rate we actually have in this country; but I would assume it is fairly safe to say that it is a unanimous feeling that mortality rates in the United States among children are higher than other certain other countries.

Can one say with any degree of unanimity what factors contribute to that higher degree? Regardless of what number we actually find ourselves in, is there a set of factors that clearly have the universe of support with regard to attributing mortality as it relates to other countries?

Dr. NEAL. I would say, Senator, that the one major factor is the lack of universal prenatal care. Too many women in this country simply do not receive it. A secondary, but less important, but nevertheless important factor is that, once they receive prenatal care, they need to be treated appropriately, which means those mothers with very high-risk conditions need to be referred to a center that can deal with that.

And those who have low-risk conditions, obviously, should be delivered as close to home as possible. So, in general, I think that there is the appropriate referral, but it could be improved upon. But by far the larger issue is the need simply to see that all women receive the care so that those high-risk conditions can be identified to begin with.

Senator DASCHLE. Is there unanimity on the panel on that? Is it lack of prenatal care that is the largest single cause for the differences which exist?

Dr. HEALY. I think the greatest reason is premature birth and low birth weight that is then directly related to lack of prenatal care; but looking at those children who experience infant mortality, there would be an extremely high relationship with low birth weight and premature birth.

Senator DASCHLE. So, you are saying that the United States has a much higher incidence of premature birth than other countries? That leads me to the obvious question: What would bring that about?

Dr. **Healy**. Lack of prenatal care, poor nutrition, poor health care practices, and just general lack of support of that woman during a very significant change in her physiology.

Senator **Daschle**. I see.

Dr. **Arant**. It is not just that prenatal care is not available. In some communities, it is; but the mother does not come to the care. Some places, the care is taken to the mother. But when you have prematurity being the issue, the younger a mother is when she has a baby, the more likely she is to have a premature baby and the higher the teenage pregnancy rate is also a large segment who deliver premature babies and also do not avail themselves of medical care, particularly early when they are denying that they might be pregnant or hoping that they might not be pregnant.

Senator **Daschle**. As one looks to the demographics of this whole thing, my hunch is—judging from the fact that we have substantially fewer physicians in rural areas than we do in urban areas—that the incidence, first, of the lack of prenatal care and ultimately of premature birth is significantly higher in rural areas than in urban areas. Is that correct?

Dr. **Neal**. No, sir, it is not.

Senator **Daschle**. It isn't?

Dr. **Neal**. Some of our worst problems and largest problems in this regard are in urban ghetto areas.

Senator **Daschle**. Oh. So, there is no relationship between the availability of physicians and facilities and the incidences of premature birth and other problems associated with mortality in early ages?

Dr. **Arant**. It is more poverty and illiteracy, I think, that where those people actually live.

Dr. **Healy**. I would agree with that.

Senator **Daschle**. Let me ask you a final question because I see my time is up, too. Dr. Neal, you said that all States ought to be required to provide some kind of prenatal care; and I assume by that you are saying that the transportation system that you have established in West Virginia could serve as some kind of a model for the rest of the country. Is that a correct assumption?

Dr. **Neal**. The model was established elsewhere. We copied it.

Senator **Daschle**. I see.

Dr. **Neal**. I think that our claim to fame, if there be some, is that we did make it work effectively; but in fact, the idea came from Canada and Scandinavian countries.

Senator **Daschle**. My real question, if the chairman will allow me, is: What I hear you saying is that the panacea, especially in rural areas, is a mandated transportation system. Is that correct?

Dr. **Neal**. The transportation system, in fact, is available to all women and all babies in our State because the very first transport that was ever done was on the premature grandchild of a State legislator. So, that is mandated and funded by legislative line item.

I think that the real issue, however, of getting women to prenatal care relates, number one, to eligibility. There are simply too many women who are not eligible for that prenatal care and, therefore, cannot afford it. Second, if all women were made eligible by mandate, then it is incumbent upon States to try and develop programs to see that they actually take advantage of it.

Because of some of these sociological factors that we have discussed, I think one of the ways to do that is to get their peers—women in the community who are perhaps just like them, but who have been selected out to literally be available to help go get these people—they are like case workers—but respected and trusted by these people because they are peers, rather than just authority figures.

There is a program like that here in Washington, D.C., and I think it is effective; and it has been shown to be effective in other places. But you are really going to have to have some way of literally getting the women who otherwise won't come and bringing them in; and that would be one way to do it.

Senator DASCHLE. Thank you.

Senator ROCKEFELLER. Just a further comment on that, Senator Daschle. I remember, Dr. Neal, when I was a VISTA worker in West Virginia 24 years ago, the problem of Pap smears provided a similar challenge. The community where I was working had no services of any sort; it was a coal mining community stretching along two sides of a creek for some miles, with very few families.

The concept of a Pap smear was really regarded as an intervention; until in the first year that I was with VISTA, none of the women at all were willing to do that. And that may have been in the way it was presented or the way it was handled. I am not sure.

But then, by the second year, they were able to; and that gets back to the fineness of sociology, of how things are presented, of [illegible] to feel that this could be beneficial. And I think, [illegible] comment about peers—others who are of the community [illegible] that area; and that is tremendously significant in Appalachia.

[illegible] can be foregone by hesitant people, held up in [illegible] fearful of authority, fearful of results, fearful of [illegible] out. That is human nature.

Dr. NEAL. That is very true.

Senator ROCKEFELLER. Gentlemen, we thank you all very much. [illegible] forward to seeing you, sir, this afternoon.

Dr. NEAL. Thank you, Senator.

Senator ROCKEFELLER. Our final panel consists of Dr. Arnold Platzker, who is testifying on behalf of the American Lung Association; he is the head of the Division of Neonatology and Pediatric Pulmonary Disease at the Children's Hospital of Los Angeles; and also, Dr. Larry Silver, who is chairman of the Council on Children, Adolescents, and Their Families, American Psychiatric Association.

Dr. Platzker, would you lead off, please? We are glad to have you, sir.

STATEMENT OF ARNOLD C. G. PLATZKER, M.D., HEAD OF DIVISION OF NEONATOLOGY AND PEDIATRIC PULMONOLOGY, CHILDRENS' HOSPITAL OF LOS ANGELES AND PROFESSOR, DEPARTMENT OF PEDIATRICS, UNIVERSITY OF SOUTHERN CALIFORNIA SCHOOL OF MEDICINE; TESTIFYING ON BEHALF OF THE AMERICAN LUNG ASSOCIATION AND THE AMERICAN THORACIC SOCIETY

Dr. PLATZKER. Mr. Chairman, members of the committee, I am pleased to present my remarks today before this committee. I have abbreviated my verbal remarks because much of what I have to say is included in my written testimony.

In addition, I commend to you the report on the Federal Task Force on Technology-Dependent Children, which was presented to the Congress on the 7th of April this year. I strongly endorse that report.

I speak to you today as a member of the American Lung Association and its medical arm, the American Thoracic Society. My experience with the problem of chronic lung disease is from the perspective of the head of a large program which focuses on inpatient and home care of infants and children with both acute and chronic lung disease.

The Children's Hospital of Los Angeles is the major referral center for these infants and children in the southwestern United States. We are a tertiary referral center with over 25,000 hospital days of our 85,000 hospital days annually for infants with chronic lung disorders.

8,000 of the patients of 90,000 outpatient visits are of children with chronic lung disease. On a daily basis, one-quarter of the beds of the 330 beds of the hospital are occupied by infants and children with chronic respiratory disorders.

We care for close to four dozen infants and children at home on assisted ventilation and close to 150 infants and children at home who receive oxygen therapy.

Thus, we have had significant experience with both the benefits and certainly the barriers to successful care of chronically ill children. We believe that, while a chronically ill child benefits greatly medically, developmentally, and clearly psychologically from home care, there are at present major obstacles in the path of providing optimal home care programs for these children and their families.

In this testimony, I will address three major issues: why home or residential, rather than hospital care; obstacles to the care of these children outside the acute care hospital; and suggestions for improvement of the home care problem.

The mission of the acute care hospital, whether it be a general hospital or a children's hospital, is the preservation of life and the management of acute illness. Thus, the hospital is not an optimal, cost-effective setting, nor can it provide the day-to-day environment for the comprehensive chronic care program with its focus on the needs of the whole child, whether these needs be medical, developmental, educational, or psychosocial.

Therefore, once a child's condition is considered chronic and the acute care needs have been fulfilled, it is necessary to look outside the hospital for a less restrictive and a more nurturing environment for long-term care. The goals of home care remain providing optimal medical care, but the focus now moves to fulfilling the complete needs of the child in the family setting.

These needs include restoring a major role for the child's care decision making to the family, eliminating long separation of the child from the family, the parent from the child, and the parent from parent—so common in long hospitalizations of children.

A final reason for championing home care is that, when appropriate resources are dedicated to it, home care is a rewarding experience for infant or child, his family, the community, and, certainly, the health care team.

We have arrived at a point in the development of medical and nursing care and the medical technology required for home care such that many of the functions of the hospital special care unit can be successfully transferred to the home setting, with no loss in quality.

We have learned that the care of children in the home by their parents is safe as well as practical. With tracheostomy care, gastrostomy, and gastric feeding tubes, respirator, cardiopulmonary monitoring, and even infusion therapy can be carried out successfully in a home setting.

There are obstacles in the path of home care. We need to develop and endorse standards for personnel and their education, equipment and its maintenance, including respirators and monitors. There is a big need for standards, for disposable medical equipment.

And while I have run out of time, I believe there is a need for entitlement of all families for a decision on home care. Thank you.

Senator ROCKEFELLER. Thank you, sir. Dr. Silver?

[The prepared written statement of Dr. Platzker appears in the appendix.]

STATEMENT OF LARRY B. SILVER, M.D., CHAIRMAN, APA COUNCIL ON CHILDREN, ADOLESCENTS AND THEIR FAMILIES; TESTIFYING ON BEHALF OF THE AMERICAN PSYCHIATRIC ASSOCIATION AND THE AMERICAN ACADEMY OF CHILD AND ADOLESCENT PSYCHIATRY

Dr. SILVER. Thank you, Mr. Acting Chairperson and other distinguished Senators. I am honored to appear before you on behalf of the American Psychiatric Association, a medical specialty society representing more than 34,000 physicians nationwide, and the American Academy of Child and Adolescent Psychiatry, a national professional association of over 3,900 children and adolescent psychiatrists.

I have submitted a more detailed statement for the hearing which includes specific recommendations and would like now to give a brief statement.

The children I speak of are not necessarily technologically dependent. They may not be in a life or death situation, but they are chronically ill; and their chronic illness, often an invisible chronic illness, impacts on the total life of the child, the total life of the family, and the total life of the siblings.

It impacts on the schools and agencies that must interact with this child and family; and, sadly, it impacts year after year after year—probably for a lifetime. These children do not die as sometimes happens with other chronic illnesses.

It is a true chronic illness. Having services that are available and financially covered is essential. As you know, it is not in place at this time, and the result is suffering for the children, the family, and the community.

The autistic child, the psychotic child, the mentally retarded child who is also mentally ill may not get the media attention of children with chronic physical illness in need of transplants or technological interventions; but their needs are just as real.

The parents of a physically ill child may feel free to stand up and speak or plead for services. The parent of a psychotic child, because of stigma, is embarrassed and says nothing. However, they hurt just as much as the parent of a child with a physical illness.

These parents, like the parents of children with chronic illnesses of other types, find their life savings wiped out. They, too, have children who continue to need services after the money is gone.

I am delighted that you are willing to hear about these children in the context of all the illnesses you have spoken of. While children with mental health problems are covered by a wide range of federally funded programs, coverage varies according to the services needed; and there is an impediment to the coordination and cooperation amongst agencies.

In addition, unlike other physical illnesses, limitations on coverage of service delivery for individuals with mental disorders exist in most private insurance programs; and in only rare instances is coverage for mental disorders equivalent to that of other physical illnesses.

Limitations on coverage result in situations where catastrophic costs can occur for families of children with mental disorders. Numerous commissions, both presidential and private, since the beginning of this century have pointed to the need for new, well-coordinated services for mentally ill children.

In addition to children who have diagnosable mental illnesses, certain environmental risk factors, such as poverty, divorce, substance abusing parents, and child physical or sexual abuse or neglect may place children at risk and require preventive early intervention.

We have effective treatments, but few children are able to receive them. The exact number of children within the population who need mental health services have not been determined adequately. There is a tendency to avoid labeling children as chronic in the context of mental disorders. We know that they exist as pervasive developmental disorders, childhood schizophrenia, severe behavioral disorders requiring long-term residential treatment, mental retardation and other developmental disabilities when there is an accompanying mental disorder.

As you know, the Federal programs that are available for these children—the Alcohol/Drug Abuse Mental Health Block Grant, Medicaid, Medicare, Champus, Public Law 94-142, and a small program called Children and Adolescent Service Systems Programs—is limited in terms of the services provided.

Medicaid services 11 million dependent children under the age of 21, but the amount of mental health services provided to this group is unknown.

The several services provided under Medicaid's early and periodic screening, diagnostic, and treatment programs is an inherited, flexible part of Medicaid; but it is not being carried out in most States.

Public Law 94-142, or Education for All Handicapped Children, provides some services; however, because of the burden of the expenses, the related necessary services for the mental illnesses are not provided.

Medicare covers some but relatively few mentally disabled children and bears importance primarily because the guidelines for Medicare have become payment rules for other services.

As the Senate Finance Committee and the Congress develop systems for the appropriate delivery of care to children and particularly children at risk or who have serious mental disorders, we would be happy to work with you; and we compliment you on trying to work for these children. Thank you.

Senator ROCKEFELLER. Thank you very much, Dr. Silver.

[The prepared statement of Dr. Silver appears in the appendix.]

Senator ROCKEFELLER. Tom, we have a vote evidently at 12:26, and it is a compromise amendment cosponsored by Senators Nunn, Warner, Boren, Cohen, and Helms.

Dr. Silver, what would you suggest that Congress and the Finance Committee do to address the problems of this particularly vulnerable segment of our population?

Dr. SILVER. I think the efforts of this committee to provide comprehensive services for a chronically physically ill child should definitely in every case include the chronically mentally ill child since that is a subgroup of the physically ill child. That has not been true in most federally funded programs or State funded programs around the country.

We ask only for parity for an equally disabling disorder.

Senator ROCKEFELLER. How do you explain the fact that you have been left out?

Dr. SILVER. I think traditionally, going through the history, the mental illnesses have not always been seen as part of physical illnesses; and yet, they are. And I think stigma has been the major issue. It is very easy for a parent to come before a Congressional committee of any type and plead for their physically ill child.

It is difficult to get a parent to stand up and plead for their mentally ill child. I don't think it has been done in a harmful way as much as by default; and it is necessary now to try and correct that problem.

Senator ROCKEFELLER. How can mental illness be financially catastrophic for children and their families? Could you describe how that works?

Dr. SILVER. Take, let's say, an autistic child diagnosed at usually somewhere between year one and year two. This is a child who will need special educational services throughout his or her childhood and adolescence, and some school districts do not provide that. Therefore, the families get involved in providing that service.

They will need extensive psychiatric care for treating the child, medical care in terms of medications, and help for the entire family, as is true with all physical illnesses or chronic illnesses. You need to do a support system for the family.

As the child gets older, the availability of services through the school system decrease; and yet the need for services increases. For the autistic child or psychotic child as they get older, they may need residential treatment or group care or respite care so that the family has some relief to take care of their other children.

So, there is a parallel in terms of all the services that are needed for physical illness.

Senator ROCKEFELLER. How much of a role does a parental sense of guilt play in the mental disorders as opposed to some of the physical disorders that we have been talking about? And I put that in the perspective of parents coming forward to deal with the problem on a constructive basis.

Dr. SILVER. I believe it is more difficult for a parent of a child with a severe behavioral or psychiatric disorder to feel comfortable going forward for help. Often the services are less available and, therefore, it is harder to seek it out.

It has been harder until recently with the new organization for these parents to gel together and try and help each other in support groups because of the embarrassment or the stigma that goes with the disorder.

Even though almost all of the chronic mental illnesses of children and adolescents have a neurologic or biological basis to it, there is still a belief by parents that it is due to bad parenting or something that they did wrong.

Senator ROCKEFELLER. What percentage of them are, as you say, preordained?

Dr. SILVER. The best statistics we have suggest that about one percent of children, or about 500,000, have what we could call "chronic mental illnesses."

Senator ROCKEFELLER. I am sorry; I don't think that was the question I want answered.

Dr. SILVER. I am sorry.

Senator ROCKEFELLER. Your last statement that the overwhelming majority of mental illness is not caused by something that happened because of parenting but was genetic or whatever. What percentage of the 100 percent does that represent?

Dr. SILVER. I can't give an exact figure. I think if we look at the major illnesses—such as autism, pervasive developmental disorder, childhood psychoses, schizophrenia of adult form that starts in childhood—my own bias would be to say that 100 percent of them are due to a neurobiological type of cause. Others in my profession may make that a little bit less.

Senator ROCKEFELLER. All right. Access to coverage in public and private programs is different for all children. Why is coverage of mental disorders in children worse?

Dr. SILVER. I would like to accept that as a rhetorical statement and just say it shouldn't be. I can't answer that; but as we look at the various legislation over the years—under Medicaid, under Medicare, under Champus, for third party carriers, even our HMO programs—there is a tremendous difference, there is a tremendous discrimination between physical illnesses and mental illnesses in terms of the amount of services provided. I don't condone that.

Senator ROCKEFELLER. I really agree with you, not having thought about it that much before, that media attention works to the disadvantage of mental disorders. I think back to the little girl who went down the well in Texas—and the world stopped. We followed her physical rehabilitation almost week by week.

There are so many examples of parents with children who are harmed physically or who have physical disabilities; and as I think back, I am trying to think of media attention given to mental disorders. Have I seen that on the 6:00 news or the 6:30 news. How much have I seen of that?

And it occurs to me that I have seen very little; and that, in turn, the media sometimes affects—rightly or wrongly—public policy. That is a substantial disadvantage for you, isn't it?

Dr. SILVER. Yes, sir. Also, if a mother goes on television to plead that: If I don't get a transplant, my baby will die; and that will cost $100,000. Every local fire department starts a funding raising.

Senator ROCKEFELLER. Or television reports on the carrying of the organ to the plane and on and on?

Dr. SILVER. Yes, but if a psychotic child who has not received the proper treatment burns down a school or injures someone, usually there is anger and rage at this child rather than understanding that that is an illness also; and that what you are seeing is the product of lack of treatment, just as the child who dies for lack of treatment for a physical illness.

Senator ROCKEFELLER. So, it is not just a question then of parental hesitation to come forward, but a community hesitation?

Dr. SILVER. I think we start with the stigma that mental illness was due to the possession by the devil and being burned at the stake as witches; and we have come a long way, but we haven't come far enough.

Senator ROCKEFELLER. Did you say 99 percent of mental disorders were in some form genetic; or in other words, not post-birth?

Dr. SILVER. No, sir. I was listing certain types of chronic disorders.

Senator ROCKEFELLER. Make the question easy for me.

Dr. SILVER. All right. For autistic, childhood schizophrenic, pervasive developmental—the severe mental disorders of children and adolescents—the research strongly supports the fact that this is due to a neurological or a neurochemical deficit.

In some cases, it is inherited; it is a genetic pattern. In other cases, we don't understand the cause yet.

Senator ROCKEFELLER. How do the doctors, how do community programs, how do the hospitals, how does anybody work with parents to encourage them to come forward?

Dr. SILVER. I think there are tremendous parent support groups beginning to evolve, such as the National Alliance for the Mentally Ill, that tries to pull together parents of the mentally ill individuals and get them to help. We have a lot of campaigns that are going on, such as the one sponsored by the National Institute of Mental Health, to destigmatize, if you will, mental illness.

We have done a major effort to try and turn that around; and I think the frustration now is that, when parents do begin to come forward, they don't find the services that they need.

Senator ROCKEFELLER. Dr. Silver, thank you.

Dr. SILVER. Thank you.

Senator ROCKEFELLER. Dr. Platzker, I was interested when you were talking about home care; and I think you said—or at least I wrote it down—that it is safe, if it is done well—safe as well as practical. I think you used that phrase.

Dr. PLATZKER. Yes. It is safe as well as practical when the resources that it requires are applied to it. That is, with today's technology and the focus of especially academic hospitals toward teaching and teaching of families to care for their children, many of these children are discharged with the family knowing how to care for the child, especially the mother.

For example, in our institution we require one other family member or friend who will come in and share the care. However, that does not supply 24-hour care; and for a child on a home ventilator, we need between eight and 24 hours of care from a nurse or someone skilled in nursing techniques to make home care realistic.

Senator ROCKEFELLER. When I think of a hospital room, there is a very clear picture that comes to mind; and that is a totally prepared room with just machinery and outlets for plugging in potential machinery everywhere, immediate service, total preparation.

When I think of a home, particularly in a rural area, but perhaps anywhere, I think of a couple of plugs in the wall; and everything appears to be deficient. Then you say, well, but the mother can be trained, or a parent can be trained. Maybe the mother is working, and maybe the father is working; or maybe they are both working.

I want you to make your point strongly because I find it so stunningly hopeful that this actually can work because it would appear to a layman that it just could not—either by the availability of the equipment, or of the attention—because in so many families, both parents do have to work if, in fact, they are together at all.

Dr. PLATZKER. In my testimony as well, I pointed to the need for national standards for disposable medical equipment and for medical support devices. This remains.

However, under the best of circumstances, the home ventilator is also one which can be battery-operated. The cardiorespiratory monitor is one which also can be battery-operated. Many of the other techniques can go without electrical support for short periods of time.

One of the barriers to discharging these infants and children, as I think you have already discerned, is that we need to assess the home and its readiness for the child. This frequently doesn't occur until late in the child's hospitalization.

We need better techniques for identifying at an early point in time which infants and children will be technology-dependent and which homes may provide an appropriate care setting for that child; and if it is a home in which the family wants the child and it is not appropriate, we need to define ways to make it appropriate.

Senator ROCKEFELLER. If I think of some homes in Appalachia, I would have to judge that the room which probably sleeps two or three children, would not be appropriate. If I think of an urban ghetto situation, I don't know what causes me to think that that room or that home would not be appropriate. This must be a large problem for you.

Dr. PLATZKER. Some homes are never going to be appropriate, and some families will never accept the care of the child at home. We need a spectrum of alternatives: medical foster placement, group homes, intermediate care facilities, all of which can support a segment of these infants and children.

We also need a greatly more flexible view of the care providers. If we are talking of eight hours of care a day for a child by a registered nurse, we are talking a minimum of $110,000 a year spent on nursing care.

Senator ROCKEFELLER. For the one patient?

Dr. PLATZKER. For the one patient. Other countries have addressed this issue in a much more innovative fashion. For example, the United Kingdom for discharge of small infants has a program of home health care aides. These are usually young girls who have graduated high school, who have learned home economics techniques—how to take care of a home, how to cook, how to take care of well children as well—but they have also learned the same skills that the child's family have learned in the hospital; and they can go home.

And if the mother says, "I will take care of my sick child now," these care takers feel very comfortable making the beds, preparing dinner for the husband, wife, and other children; and they do splendidly. And the cost to the government is substantially less than having registered nurses in the home.

Senator ROCKEFELLER. And how much less?

Dr. PLATZKER. It may be as much as 50 percent less.

Senator ROCKEFELLER. Home health nurses——

Senator CHAFEE. Mr. Chairman, did you forget us on this side of the table?

Senator ROCKEFELLER. I am sorry, Senator Chafee. I thought that you had departed; I am very sorry. Senator Chafee? No, let me just finish my question.

(Laughter)

Senator ROCKEFELLER. I really do apologize; I did not look to my left. The home health nurse associated with home health care for, let's say, Medicare—older patients—that seems to be a profession which is fairly well recognized. I have gone on many occasions with them to homes. Now, is there a similar budding profession or, in fact, a very extant profession which I am simply unaware of, of the home health nurse who deals with these very, very young children?

Dr. PLATZKER. Yes, there is. They are a valued resource, but they are scarce. And in essence, it may be better to have nurses act as supervisors of the care of other less skilled individuals than committing them to the bedside of a single child.

In other words, one mobile nurse in an urban environment can supervise and consult on the care of a dozen children in the home situation during a day and would be a much more important resource in keeping these children at home than placing the nurse with one technology-dependent child.

What I am saying is that in the home setting, a motivated mother can care for the child until she needs to go to the grocery store, go to sleep, or go to work; and she could be replaced by an equally well trained home health care aide under the supervision of a registered nurse who is trained in these techniques and can supervise the level, quality, and adequacy of the care of other less expensive care givers.

Senator ROCKEFELLER. Thank you, Dr. Platzker. I genuinely apologize to you, Senator Chafee. Please go ahead.

Senator CHAFEE. I found your line of questioning very interesting; so I was delighted to hear what you were asking and the answers.

Dr. Platzker, what I would like to ask, pursuing what Senator Rockefeller was saying about the home care, it is my deep belief that children do better in a home setting than they do in a hospital setting. That seems to be what you are saying here.

There are problems; sure, there are problems. But if we can provide the equipment and the respite care that you were discussing, it is better off—it seems to me from every respect—and let's start with the child's welfare, for the child to be in his or her home. Isn't that a truism?

Dr. PLATZKER. Yes, I believe that is true. It requires good case management—very good case management—and it needs to be centralized to assure that the adequacy and quality of the home care conform to appropriate standards.

Senator CHAFEE. A question for Dr. Silver. Just as the mental health of a child or an adult affects his or her physical health, there is a vice-versa to it also, isn't there? A physically healthy child has probably a greater opportunity to be mentally healthy; is that a fact?

Dr. SILVER. That is correct. And as you have heard from all the people testifying today, when someone has a physical illness, we must address their mental health needs as well.

Senator CHAFEE. And everything that has gone on with the prior testimony dealing with proper prenatal care and the return to society of a mind relieving the anguish of the child or the parent, everything that has been said about proper prenatal care applies to the mental health of the child in the future likewise, does it not?

Dr. SILVER. Yes, and the mental health of the mother.

Senator CHAFEE. And the mental health of the mother. Mr. Chairman, these hearings have been very, very helpful. I know that if we listen to the statistics, one can get discouraged and say: Stop the world; I want to get off. But at the same time, it seems to me, it lays out for us a clear challenge.

Every challenge is an opportunity, an opportunity I believe for this Congress and this committee to make some really constructive progress in these areas that you are so concerned with, as the rest of us are likewise.

So, to me it looks like a restructuring in many respects of our health care system. It is certainly a broad extension of Medicaid coverage. So, these hearings have been very, very helpful; and I am glad we held them.

I look forward to further such hearings, and let's see if we can't now follow up with some corrective legislation. Thank you, Mr. Chairman.

Senator ROCKEFELLER. Thank you very much, Senator Chafee. Gentlemen, we thank you. I am new to this committee; I don't know how often you come and testify, but it must seem like a bizarre procedure to travel a great distance and then to be questioned at short length and have red lights go off and then back to your seat and then back home.

But it is a very valuable process to us; it obviously goes on the record, and it helps to build a case hopefully for good action. Thank you so much.

Senator CHAFEE. I would like to join in thanks. As you mentioned, Mr. Chairman, these gentlemen come a long way. Dr. Platzker has come from Los Angeles.

Dr. PLATZKER. Yes, and I am going to Blackstone Boulevard tomorrow.

Senator CHAFEE. Are you really? To Butler Hospital?

Dr. PLATZKER. No, to my in-laws' house for dinner.

(Laughter)

Senator ROCKEFELLER. Thank you very much, gentlemen. This hearing is adjourned.

[Whereupon, at 12:23 p.m., the hearing was adjourned.]

APPENDIX

ALPHABETICAL LIST AND MATERIAL SUBMITTED

Billy S. Arant, Jr., M.D.

The United States currently faces a crisis of major proportion in providing health care to children with chronic illness due to kidney disease. The problem is manifold. First, the financial impact of chronic renal disease on a child and his or her family can be devastating. When faced with a prenatal finding of abnormal kidneys in the unborn child and information about the costs of providing medical care to the child following birth, parents are being forced to consider measures to intervene in the pregnancy--even when effective treatment is available, but unaffordable. Secondly, as advances in medical knowledge and technology have saved the lives of neonates, infants, children and adolescents who previously would have died, the number of children requiring medical care for kidney-related disorders--some actually caused by the successful treatment of premature birth, cancer and heart disease--has increased dramatically. Thirdly, there are too few physicians trained to provide the specialized care required for infants and children with kidney disease. In some regions of the country--entire States, in fact--such care is not available at all.

The Cost of Medical Care for Children with Chronic Kidney Disease

Often, costly medical and surgical care of a child with kidney disease occurs before the full earning potential of parents has been attained. Children born with or who develop renal disease after birth are usually excluded for as long as 90 days or denied insurance benefits altogether because of "pre-existing" illness. In view of the enormous cost of neonatal intensive care, this results in an unacceptable burden for almost all affected families. The expensive treatment of children with kidney disease is usually not available in public hospitals. With an increasing number of patients needing medical care but with fewer possibilities reimbursement, patients and their families are soon rendered indigent by the costs of treating kidney disease of just one child. Moreover, it is not unusual for two or more children in the same family to have the same kind of kidney disease.

Whereas Title 5 (or comparable state-support programs) covers urologic, neurologic, cardiologic and hematologic conditions, most renal conditions and excluded prior the the time complete kidney failure occurs which could be a matter of months to as long as 12-15 years. The cost of providing medicines, nutritional supplements, psychiatric and psychological services, educational resources and nursing are not provided by private or governmental third party health cost providers. Middle income families may have enough resources to preclude eligibility for government-funded medical care for their children with renal diseases. Although adequate funds are available for children with end-stage renal disease through Medicare, the majority of infants and children with congenital or inherited renal disorders have renal insufficiency that is debilitating and expensive but not funded until the criterion of "end-stage renal disease" is met. Even for children with kidney failure, the fraction not covered by Medicare, as well as the cost of medications and transportation to a tertiary care center, results in overwhelming debts. Private foundations have not filled the gap. It is essential that funds be made available to those families that have no other resources.

In most infants with renal disease, frequent follow-up is necessary because of complex treatments, including multiple medications, nasogastric tube feedings, and dialysis. The complex treatment and frequent travel to a medical center is disruptive to families with increased expenses for transportation, loss of work, and neglect of healthy siblings. These problems are even greater in rural areas where distance between the patient and the medical center may be hundreds of miles or across State lines.

Failure to recognize the additional financial requirements of providing the best medical care for neonates, infants, children and adolescents with chronic renal disease has contributed to the growing frustration and declining numbers of pediatric nephrologists in the United States. The U.S. Government now spends nearly $3.0 billion annually through Medicare to treat end-stage renal disease, mostly in adults -- 80% developed kidney failure because of a disease, like diabetes, which began during childhood. To date, no federally-funded research programs have been directed towards preventing these diseases; however, many programs have been funded to develop new treatment strategies for kidney diseases in adults which began in childhood--too late, perhaps, to interrupt the progression of renal injury. While these programs are important ones, there is little doubt that developing programs to identify kidney damage during childhood would be more cost effective and would serve to relieve the growing financial burden for treating the consequences in many of these diseases in adults.

Increasing Clinical Burden of Providing Medical Care for Children with Chronic Kidney Disease

There are approximately 220 pediatric nephrologists in academic institutions within the United States currently providing medical care to children with kidney disease. Effectively, there is one pediatric nephrologist for every 200,000 children. By contrast, there is one general nephrologist for every 60,000 adults. In addition to the relatively fewer nephrologists,an increasing number of renal-related problems in children has increased the clinical burden on each pediatric nephrologist employed in patient care. When one considers both symptomatic and incipient clinical nephrology problems which face pediatric nephrologists, the task required to meet these clinical challenges is formidable. Consequently, a large segment of the U.S. population being underserved, even denied access to such specialized medical care.

Of the 200,000 children who will depend upon one pediatric nephrologist, 12,000 will develop urinary tract infections each year, 5,000 will have vesicoureteric reflux leading to permanent kidney damage in 2,000 of them; 5,000 will require evaluation for protein in the urine; 2,000 will be evaluated for blood in the urine; 1,000 will develop diabetes - 40% of them will ultimately become uremic adults and require dialysis and transplantation; 7,000 will develop kidney stones at sometime during their lifetime; 10,000 will have hypertension and 50,000 others will become hypertensive at an older age, and at least 20 others will require dialysis or transplantation for other causes during the first two decades of life.

Clinical care by physicians for adults with kidney failure can be measured in accumulated hours or days. The time for initiating and completing similar care for the infant and young child is expressed more realistically in increments of weeks and months. While nephrologists in the field of internal medicine may be able to reduce some of the clinical burden by assimilating older children and adolescents into their practices, the largest group of new patients requiring specialized care are those who survive the newborn period with impaired kidney function--the likes of which the internist is neither trained nor prepared to treat.

The patient population served by the pediatric nephrologist is undergoing continued somatic, mental and psychosocial maturation. The clinical problems of the very premature infant in whom the kidney is not yet fully formed is vastly different from the adolescent patient who requires transplantation who seeks peer acceptance and personal independence. Often the imposition of stresses of chronic renal disease upon the normal tribulations of childhood disrupts family life, limits social performance and results in patient non-compliance. In order to address and anticipate the inevitable problems of chronic renal failure, dialysis treatments and transplantation, a team of medical professionals is required. The leader of this team is the pediatric nephrologist who must coordinate the efforts of nutritionists, social workers, psychiatrists, hospital based school teachers and nurse specialists in providing total care for children with chronic renal disease. Divorce and marital strife, financial difficulties in the family are typical for children with any chronic disease which further complicates the personal development of children with kidney failure.

The past decade has seen, the emergence in children of new disease and morbidity related to advances in medicine and medical technology as well as the application to pediatric diseases of technology previously available only to adults. Many of these changes have increased the burden on pediatric nephrologists to provide inpatient tertiary level care. Changes that have and will continue to increasingly have an impact upon pediatric nephrology include acute renal failure associated with cardiac surgery in the very young; the nephrotoxicity of drugs, including cyclosporine A, antibiotics, nonsteroidal antiinflammatory agents and anticancer agents; the increasing number of pediatric and neonatal intensive care units with its attendant increase in the number of patients who develop renal failure; the increasing number of organ transplants, including heart, liver, and bone marrow, which as part of their spectrum of complications, include renal failure (a majority of children who have successful bone marrow transplants for cancer in France subsequently develop irreversible kidney failure secondary to the damaging effects of chemotherapy and radiation); the increasing number of renal diseases for which kidney transplantation is possible, including oxalosis and the transplantation of children less than one year of age who, until recently, were denied treatment because of the technical limitations and clinical inexperience; the recognition of genitourinary malformations in utero, for which intrauterine therapy and or immediate neonatal therapy may be beneficial; the application of dialysis treatments, including various forms of peritoneal dialysis and hemodialysis to newborn, not only to treat renal failure but to treat endogenous (hyperammonemia, hyperaminoacidenmia) and exogenous (drug) toxicity; short-term and long-term problems related to extracorporeal membrane oxygenation; renal vascular lesions related to the used of indwelling arterial and venous lines in neonates; the application of continuous arteriovenous hemofiltration to treat diseases and or therapies associated with massive edema and the recognition of inborn errors of metabolism associated with life-threatening metabolic consequences such as lactic acidosis, which, if recognized, may be treated successfully.

Many ethical challenges face the discipline of pediatric nephrology. Some issues relate to the allocation of resources for the provision of dialysis and transplantation to extremely premature infants, to mentally handicapped children and to non-compliant teenage patients. Moreover, there is no provision for the care of children whose conditions are treatable but who have no competent family support to assure compliance with treatment. In contrast, the benefits of such therapies in providing an acceptable quality of life for those pediatric patients has not been determined. The acceptability of organ donation from minor siblings, parents or even an anencephalic infant donor must be determined to meet the immediate demands and future needs of children with kidney disease and for those who provide their expert medical care.

Educational needs in pediatric nephrology underscore the critical shortage of pediatric nephrologists and allied health professionals required for training pediatricians in the management of renal disorders in neonates, infants, children and adolescents. In addition, since infants and children are largely dependent on their parents for compliance in medical treatment, parent and patient education is essential for the early recognition and optimal care of these complex diseases. The school teacher, counsellor and school nurse should also be better informed. Since a umber of disease affecting large numbers of adults (such as diabetes mellitus and hypertension) begin in childhood, it is reasonable and cost-effective to improve education of physicians, other health processionals, and the lay public with respect to early detection and intervention.

Manpower Crisis in Providing Medical Care for Children with Chronic Kidney Disease

It is a well-known fact that providing any service for a healthy child takes more time than providing a similar service for a healthy adult. Likewise, the chronically-ill child requires more time and resources to deliver medical care than the adult with the same disease. Based on seriously-flawed studies, the impression has been given that more physicians have been trained than are needed to provide adequate health care for the people of the United States. While this may be true for some medical specialties, it is certainly not the case for pediatric nephrology.

A pediatric nephrologist is a pediatrician with specific training to care for neonates, infants, children and adolescents with hypertension, disorders of the kidneys and abnormalities of body fluid and electrolyte composition. The pediatric nephrologist is the resource in the community for the generation of new knowledge in basic and clinical research in childhood kidney-related diseases and for the education of medical students, resident physicians, pediatricians, family practitioners and graduate students not only in the clinical management of pediatric kidney diseases but also in the mastery of nephrological research. The pediatric nephrologist, then, is the individual responsible for the application of the latest methodologies of molecular and cell biology, genetic, physiologic, and immunologic research and clinical innovations which will allow the prevention, modification or resolution of kidney disorders in children. Furthermore, as pediatricians, they have both special interests in the physical and mental development of children and specific training in nutrition to optimize growth and to prevent or modify nutritionally-related diseases.

The clinical responsibilities of the pediatric nephrologist include the detection, prevention and intervention of disorders which are manifest or have their beginnings during childhood and will adversely influence health during a lifetime. Certain disorders, such as acute kidney failure in neonates, are easily identified as problems for pediatric nephrologists. Others, such as diabetic nephropathy, hypertension, kidney stones or cystic kidneys have their genesis in childhood but are mistakenly believed to be adult diseases. In providing a wide range of clinical services, pediatric nephrologists are almost exclusively practitioners in academic or tertiary care centers where they evaluate many children with such common clinical problems as hypertension, urinary tract infection, proteinuria and hematuria, they supervise the dialysis and renal transplant programs, and they serve as consultants for the most critically ill neonates and older children with intrinsic kidney disorders, or more often, with injury to the kidney from applications of the latest life-saving technical and medicinal therapies. Frequently the personal time commitment for the provision of these consultative services far exceeds that of the intensivist or primary care providers.

In a recent survey conducted by The American Society of Pediatric Nephrology, 93% of Chairman/Program Directors of U.S. medical school-affiliated pediatric training programs confirmed the manpower shortage extant already in pediatric nephrology. This manpower shortage will become even more critical over the next five years. This finding is in marked contrast to situations in Europe, Australia and Japan where experienced pediatric nephrologists cannot find permanent positions. At the present time there are approximately 40 full-time positions in pediatric nephrology in the United States which are unfilled. The demand for these positions has been created mostly by the increased recognition of kidney disease in children and the development of new techniques for treating these conditions. There are 10 states, for instance, which have no resident pediatric nephrologist and must depend upon the resources of neighboring or distant medical centers to provide specialized consultation and care for their young citizens. Moreover, 11 states have only one pediatric nephrologist, and seven states have only two pediatric nephrologists working together in the same major city. There is a projected need for 125 additional pediatric nephrologists in the United States by 1992. This estimate is considered to be conservative one. Due to the escalating clinical demand placed upon the dwindling number of pediatric nephrologists currently engaged in clinical patient care, the United States faces a critical manpower shortage within the next 10 years when it will no longer be able to meet the needs of its children for the same treatment of kidney disease now afforded adults.

Opening Statement of Senator Lloyd Bentsen
Finance Committee Hearing on
Primary Health Care for Children
May 24, 1988

This morning, we are holding the second in a series of hearings on health care issues affecting children. Today's hearing will focus on issues related to primary care services, including the reduction of infant mortality rates, maternal and child health and other special concerns. There is a great deal of interest among members of this Committee in these issues, and I hope that this morning's hearing will generate a continuing discussion of how best to guarantee our children a healthy start in life and access to basic health care services.

I am especially pleased that my distinguished colleague, Senator Chiles, will be joining us today to comment upon the work of the National Commission on Infant Mortality, which he has so ably chaired for the past year. Last fall, when I introduced legislation to create a National Commission on Children, I indicated that I hoped to make 1988 the year during which child health issues would become the priority agenda item for the Committee on Finance. The Infant Mortality Commission has done a fine job of laying the groundwork for the work of the children's commission, and I am grateful to Senator Chiles for his efforts.

It is well known to members of this Committee that, as a nation, much remains to be done to improve basic health services to our children:

The United States ranks seventeenth among the

> developed countries of the world in infant mortality rate. We have made no progress in this area at all since 1985. A white infant born in this country is two-thirds more likely to die in his first year than a baby born in Japan. A black baby born here in Washington, or in many other of our nation's cities, is more likely to die before its first birthday than a baby born in Jamaica.
>
> The Guttmacher (GOOT-mock-er) Institute, from whom we will be hearing today, recently reported that as many as 35% of American pregnant women get less than sufficient prenatal care. This, despite evidence that investments in prenatal care are returned three to one during the first year of an infant's life.

At our first hearing on this subject in March, we heard from the Office of Technology Assessment that the United States is not doing as well as it could in preventing health problems in children. OTA reminds us that preventing or treating health care problems in early childhood can benefit a child for a lifetime, and that investing in improvements can pay off handsomely by guaranteeing us a next generation of healthy, productive adults. We also know that some American children -- those from low-income families, and those with limited access to health insurance -- are at particularly high risk.

Today, we will hear from a broad spectrum of witnesses about strategies to improve access to primary care services for children. There are success stories to be told, I'm sure.

On the other hand, we have much farther to go to assure that all children have access to adequate and affordable health care. Failure to grapple with the problems faced by children and their families will shortchange this country of the strong and healthy leaders we need in the next generation.

There is no one who is more aware than I of the difficulty of improving child health programs in a time of budget constraints. But we should not be deterred from a task that both compassion and cost-effectiveness tell us we must meet.

STATEMENT OF

HELENE BOTSONIS, R.N.

Mr. Chairman and members of the Senate Finance Committee, I am Helena Botsonis from Amarillo, Texas. I am a member of the March of Dimes National Council of Volunteers and also the Texas Volunteer for Public Affairs. I would like to thank you for inviting me here today to express the views of the March of Dimes Birth Defects Foundation on the importance of health care programs to the lives and health of our nation's children. The March of Dimes has been working for 50 years to improve child health in this country. The past 30 years have been devoted to preventing birth defects and helping ensure that all babies get a healthy start in life.

The March of Dimes is especially concerned with the alarmingly high rates of low birthweight and infant mortality in this country. Today, we would like to focus attention on strategies that can improve the nation's maternal and child health care system and reduce the rate of infant morbidity and mortality. This testimony will outline three steps for improving our national system:

1. Strategies proven effective which should be immediately implemented nationwide,

2. Innovative programs expected to be effective that should be studied and replicated through demonstration projects, and

3. Areas in which further research is needed.

Mr. Chairman, we commend your commitment to the health and welfare of mothers and children and are encouraged by the work of this committee and these hearings. A national commitment to improving maternal and child health has been proven to dramatically decrease the incidence of low birthweight and infant mortality.

This has been proven in many countries but perhaps nowhere more dramatically than in Costa Rica -- a country with very little money and few technological resources available for mothers and infants. They lowered their infant mortality rate from 62 per thousand live births in 1970 to 17 per thousand in 1986. They did it by making child health a top priority and implementing a program that made health care available without financial barriers.

What does the U.S. need to do? Ensure available, accessible, acceptable and adequate prenatal care, delivery and postpartum care for every pregnant woman. And ensure that those children born prematurely or with a birth defect receive the care and treatment they need.

THE FIRST STEP IN IMPROVING OUR NATIONAL MATERNAL AND CHILD HEALTH CARE SYSTEM IS TO IMPLEMENT STRATEGIES THAT WORK.

There are five strategies that have proven effective: Raising the income level for Medicaid eligibility for pregnant women and infants to the federal poverty level; reducing non-financial barriers to care; improving coordination among existing programs; strengthening the Maternal and Child Health Block Gránt; and assisting families of infants who incur exorbitant medical bills.

THE MEDICAID ELIGIBILITY FOR PREGNANT WOMEN AND INFANTS MUST BE RAISED IN ALL STATES TO THE FEDERAL POVERTY LEVEL.

Numerous studies and reports on reducing low birthweight have recommended that all women should have prenatal care. The Southern Regional Task Force on Infant Mortality, the Institute of Medicine, the Office of Technology Assessment and the General Accounting Office have all attested to the effectiveness and cost-effectiveness of prenatal care.

Medicaid is the largest payer of maternity care for women living in poverty; yet many poor women either are not eligible for Medicaid or are unable to receive care because of non-financial barriers. We have made significant improvements in Medicaid eligibility since 1984 and legislation is pending to further increase the number of eligible infants and pregnant women.

Through the Medicaid options to increase income eligibility to 185 percent of the federal poverty level, we have increased dramatically the number of women who potentially have access to maternity care. However, the least we must do is to insure Medicaid coverage for women up to 100 percent of the federal poverty line in all states by enacting S. 2122 or S. 2046 to mandate the SOBRA option.

The March of Dimes will continue to advocate state expansion of Medicaid to 185 percent of the poverty level for pregnant women and infants.

WE MUST REDUCE NON-FINANCIAL BARRIERS TO MATERNITY CARE THROUGH EXISTING PROGRAMS.

Even if all women with incomes below 185 percent of the poverty level become eligible for Medicaid maternity care, there are non-financial barriers to receiving care.

The Consensus Conferences on Access to Prenatal Care and Low Birthweight, which the March of Dimes funded, identified a number of provider, patient, and "systemic" or public policy barriers to care. We have limited discussion here to barriers that can be addressed through legislative initiatives, including:

o Multiple and confusing eligibility requirements for benefits;
o Inadequate provider reimbursement;
o Inadequate outreach and follow-up;

- o Maldistribution of providers;
- o Underutilization of certified nurse-midwives and nurse-practitioners; and
- o Lack of transportation and child care for prenatal care visits.

The 1988 Bradley-Waxman bill provides incentives for addressing barriers in some of these areas. It is important that the federal government provide incentives -- through Medicaid, the Maternal and Child Health (MCH) Block Grant, or other programs -- for states to develop effective means to eliminate barriers in their communities.

WE MUST IMPROVE COORDINATION AMONG EXISTING PROGRAMS TO PROVIDE COMPREHENSIVE SERVICES TO PREGNANT WOMEN.

In addition to Medicaid, the MCH Block Grant and the community and migrant health centers (CMHC) are important providers of health care for women and their children. It is important to realize that MCH and health centers provide **only** prenatal care. Therefore, coordination between health centers, MCH and Medicaid is needed to help clinic patients gain access to labor and delivery services.

The WIC program must also be closely coordinated with MCH, CMHC and Medicaid. A pregnant woman should be able to go to one place to receive health and nutrition services, and get referrals to other services she may need, such as substance abuse counseling or food stamps.

In 1987, $20 million for an infant mortality initiative was appropriated to the community health centers programs. Efforts are being made to use this money to improve coordination among the various federal programs at the local level to provide comprehensive services to pregnant women. The March of Dimes looks forward to working to improve coordination of services on the local level when the grant monies are distributed.

WE MUST STRENGTHEN THE MATERNAL AND CHILD HEALTH BLOCK GRANT.
Through the MCH block grant, states provide prenatal care to about 400,000 women annually. There is great diversity among the states in the use of MCH monies -- as was intended by formulating the block grant. However, we need an accurate assessment of how each state uses its MCH dollars. Improved accountability would allow the federal government to oversee the program, monitor progress and provide a way for state MCH programs to learn from each other.

We are concerned that the MCH block grant does not have a "maintenance of effort" requirement, and that in some states increases in federal funding are supplanting state funds. In addition, we are concerned that some states are withdrawing MCH funds from public health clinics and putting this money into Medicaid to draw the federal matching dollars. Women previously served through the MCH program, who may not qualify for Medicaid, are no longer covered in these states. These states are negating the opportunity Medicaid expansion provides for serving more poor women.

WE MUST ASSIST FAMILIES OF INFANTS INCURRING EXORBITANT MEDICAL BILLS.
About 9,500 babies born each year require hospital care whose costs exceed $50,000. Parents often have difficulty in obtaining assistance to pay for this care. A bill introduced last year by Senator John Chafee would help these parents through the MCH block grant.

The proposal would provide case management services to infants with high medical bills, and in the case of those infants with medical bills exceeding $50,000, MCH would be the payer of last resort. The

March of Dimes supports this legislation as one way to reduce the financial burdens for families of children born with birth defects.

THE SECOND STEP IN IMPROVING OUR NATIONAL MATERNAL AND CHILD HEALTH CARE SYSTEM IS TO TEST OUT NEW STRATEGIES.

FIRST, WE SHOULD EXPLORE STRATEGIES TO INCREASE THE AVAILABILITY OF PROVIDERS OF MATERNITY CARE.

There is a lack of obstetrical providers in many areas of the United States. The cost of malpractice insurance and the threat of malpractice have discouraged many physicians from continuing their obstetric practice. In addition, problems with Medicaid -- including low reimbursement rates, delayed payments and administrative burdens -- further restrict access to care for low-income women.

Several states are conducting demonstration projects to address the lack of prenatal care that is resulting from the malpractice insurance crisis. Strategies that are being considered include: paying a provider's liability insurance, establishing malpractice insurance risk pools for providers of obstetrical services for low-income women, and ensuring risk-appropriate care for pregnant women. We encourage Congress to provide incentives to all states to implement these demonstration projects.

The March of Dimes supports studies and data collection on provider reimbursement and participation rates because this information is helpful in evaluating certain programs and determining directions for the future.

WE MUST ENCOURAGE STATES TO DEVELOP INNOVATIVE FINANCING STRATEGIES.

Programs like RIte Start in Rhode Island, Jerseycare in New Jersey and Healthy Start in Massachusetts provide health care services to low-income pregnant women who do not have health insurance coverage and who are not eligible for Medicaid. In these programs, the state uses its own resources to finance the care.

Other states prefer different approaches to financing maternity and child health care, such as a Medicaid "buy-in," state subsidized insurance premiums, and shared-risk pools. The March of Dimes supports these state efforts.

Senator Chafee has proposed legislation to permit states to expand Medicaid programs with matching federal funds, allowing for Medicaid buy-ins. Proposed options include allowing people with pre-existing conditions who have been refused insurance or who have exhausted their private coverage to buy into Medicaid for an income-adjusted premium. Another option offers employers who can't obtain private coverage for their employees at a reasonable cost the opportunity to buy Medicaid coverage for their workers.

This legislation provides federal leadership and incentives to states to increase access to health care.

Some states prefer private sector approaches for increasing access to maternity and child health care. These states find that "mainstreaming" families and individuals into existing private insurance is their best option. One method of mainstreaming involves the state paying some or all of the insurance premiums for its low-income residents. The state's share of the premium is based on the family's income.

Shared-risk pools offer comprehensive major medical insurance to people considered high-risk by insurance companies. Many of these people, including children, have birth defects or chronic illnesses resulting from low birthweight, which keep them from obtaining individual health insurance.

WE MUST DEVELOP EFFECTIVE OUTREACH PROGRAMS AND INCENTIVES FOR PRENATAL CARE.

In conjunction with increasing access to health care, and insuring an adequate number of providers, the U.S. needs to encourage pregnant women to use the system. The first step is to let them know that they can gain access to the health care system -- and that they will be treated with respect. We also need to continue public health education about the importance of prenatal care, and the hazards of smoking, drinking and using drugs during pregnancy.

The March of Dimes is working on a number of projects with this goal in mind. Here in Washington, we collaborate with Blue Cross/Blue Shield and WRC-TV, the local NBC affiliate, on the "Beautiful Babies Right From the Start" campaign. You may have seen the campaign's public service announcements or the documentaries on television, but there is another crucial component to this project. A coupon book, containing important health information for pregnant women, was mailed to women who responded to the television advertising. Once validated by a health care provider during the woman's prenatal visit, each coupon provides a discount on goods or services typically purchased by women.

THE THIRD STEP IN IMPROVING OUR NATIONAL MATERNAL AND CHILD HEALTH CARE SYSTEM IS TO CONTINUE RESEARCH INTO THE CAUSES AND PREVENTION OF INFANT MORTALITY.

We know that prenatal care improves pregnancy outcome on the aggregate level. What we do not know is what aspects of prenatal care are most important. We do not even know what triggers the start of labor or what influences the growth of the fetus. This is crucial information if we are to effectively reduce the number of preterm and low birthweight births in this country. About 10 percent of U.S. births are preterm, or about 350,000 babies per year. Preterm births are more common in the United States than in many other countries and are the main cause of our ranking behind 18 other nations in terms of infant survival.

In 1988, its 50th anniversary year, the March of Dimes is initiating accelerated efforts to prevent premature labor. The March of Dimes believes that the best hope for a major reduction in preterm births is to determine how and why labor begins. We believe that this is possible, and affordable, if scientific efforts are coordinated to focus on this problem. Research in this direction, through organizations like the March of Dimes and through institutions such as the National Institutes of Health, is a critical first step in solving a major national child health problem.

CONCLUSION

If the United States is to reduce its tragically high rates of infant death and illness, we must improve our national maternal and child health care system now. This can be accomplished by:

1. Immediately implementing nationwide strategies which have proven effective, including raising Medicaid eligibility for pregnant women and infants to the federal poverty level; reducing non-financial barriers to prenatal care; improving coordination among existing programs including WIC, Medicaid and CMHC; strengthening the Maternal and Child Health Block Grant; and helping families of infants with exorbitant medical bills.
2. Studying and replicating innovative programs to increase the availability of care providers, to develop innovative financing strategies and incentives for prenatal care through demonstration projects, and

3. Continuing to conduct research into the causes and prevention of infant mortality.

The United States must make improving child health a top priority. Congress and the federal government must lead the way for states and local communities. There are bills pending in Congress which should be enacted to implement strategies which we know can improve health care for mothers and their children:

1. Mandate Medicaid coverage of pregnant women and infants living in poverty (S. 2122, S. 2046)
2. Make other improvements in Medicaid (S. 2122)
3. Allow state Medicaid "buy-in" options (S. 1139)
4. Encourage formation of state risk pools for people unable to obtain health insurance. These provisions, introduced by Rep. Fortney Stark, are in the House catastrophic bill.
5. Strengthen the MCH Block Grant by expanding its care management function (S. 1537) and by holding hearings on accountability in the appropriate Senate and House committees.
6. Provide states with incentives to implement demonstration programs to improve provider participation in Medicaid and to make the system more accessible.
7. Support adequate funding for child health and development research conducted by the National Institutes of Health.

We must ensure accessible, available and adequate prenatal care, delivery and postpartum care for every pregnant woman. And we must ensure that children born prematurely or with birth defects receive the care and treatment they need. America's mothers and children deserve no less.

Thank you.

STATEMENT BY
SENATOR JOHN H. CHAFEE
AT
FINANCE COMMITTEE HEARING ON
HEALTH CARE FOR
SERIOUSLY ILL CHILDREN
MAY 25, 1988

THIS IS THE THIRD IN A SERIES OF HEARINGS ON THE STATUS OF CHILDREN'S HEALTH CARE. OUR FOCUS TODAY IS THE PLIGHT OF CHILDREN WHO HAVE SERIOUS ILLNESSES.

I WANT TO TAKE A MOMENT, HOWEVER, TO EMPHASIS THE IMPORTANCE OF THE TESTIMONY WE HEARD ON TUESDAY REGARDING PREVENTION. I THINK WE MUST BE CAREFUL TO ADDRESS BOTH PREVENTION AND CARE FOR CHILDREN WITH SERIOUS ILLNESSES AT THE SAME TIME. WE SHOULD NOT EXACERBATE OUR SYSTEM'S EMPHASIS ON "SICK-CARE" TO THE DETRIMENT OF "WELL-CARE". THERE IS NOTHING MORE HEARTBREAKING THAN AN ILLNESS THAT COULD HAVE BEEN PREVENTED.

I AM ALL TOO FAMILIAR WITH THE PROBLEMS THE FAMILIES OF SERIOUSLY ILL CHILDREN FACE. I HAVE TALKED TO AND VISTITED WITH MANY IN MY OWN STATE OF RHODE ISLAND AND ACCROSS THE NATION.

OF ALL THE GAPS IN OUR PRESENT HEALTH CARE SYSTEM -- AND THERE ARE MANY OF THEM -- ONE OF THE MOST HEARTBREAKING IS THE PLIGHT OF YOUNG PARENTS OF CHILDREN WITH CATASTROPHIC ILLNESSES WHO FACE FINANCIAL RUIN BECAUSE THEY CANNOT MEET THE STAGGERING HEALTH CARE BILLS. FEW CHILDREN REQUIRE MEDICAL CARE THAT RESULTS IN TREMENDOUS EXPENSE TO THEIR FAMILIES. HOWEVER, WHEN THEY DO, THE RESULTS TO THE FAMILY ARE DEVASTATING. THE COSTS FREQUENTLY EXCEED EVEN THE BEST INSURANCE POLICIES.

BUT EQUALLY AS TROUBLING AS THE FINANCIAL PLIGHT THESE FAMILIES FACE IS THE WAY OUR HEALTH CARE SYSTEM CARES FOR THESE CHILDREN. THE HEALTH CARE SERVICES AND EQUIPMENT NEEDED TO BRING A SERIOUSLY ILL CHILD HOME FROM THE HOSPITAL ARE FREQUENTLY COMPLETELY UNCOVERED.

THESE FAMILIES ARE FACED WITH IMPOSSIBLE CHOICES.

IF THEY LEAVE THEIR CHILD IN AN INSTITUTIONAL SETTING -- A HOSPITAL, SKILLED NURSING HOME OR INTERMEDITE CARE FACILITY -- THEY ARE OFTEN ASSISTED BY INSURANCE POLICIES, MEDICAID OR OTHER FEDERAL OR STATE PROGRAMS.

HOWEVER, BECAUSE OF THE "MEDICAL MODEL" BIAS IN OUR HEALTH CARE SYSTEM, IF THE FAMILY CHOSES TO BRING THE CHILD HOME THERE IS LITTLE OR NO AVAILABLE ASSISTANCE.

I BELIEVE THAT IF WE ARE INTERESTED IN ASSISTING SERIOUSLY ILL CHILDREN AND THEIR FAMILIES, WE MUST RESTRUCTURE AND EXPAND OUR EXISTING PROGRAMS TO DO THREE THINGS:

1. PREVENT THE FINANCIAL DEVASTATION OF A FAMILY;
2. PROVIDE ACUTE CARE, INSTITUTION BASED SERVICES WHEN NEEDED;
3. PROVIDE A BROAD RANGE OF COMMUNITY-BASED SERVICES TO FAMILIES TO HELP THEM REMAIN INTACT.

I HAVE INTRODUCED TWO LEGISLATIVE PROPOSALS WHICH I BELIEVE GO A LONG WAY TOWARD ACCOMPLISHING THESE GOALS. S.1537, THE CARE MANAGEMENT AND CATASTROPHIC HEALTH CARE FOR CHILDREN ACT AND S.1673, THE HOME AND COMMUNITY QUALITY SERVICES ACT.

I HOPE TODAY'S WITNESSES WILL HELP FOCUS OUR EFFORTS IN SUCH A WAY THAT WE CAN MOVE FORWARD ON THESE AND OTHER PROPOSALS IN THE COMING MONTHS.

STATEMENT

by Senator Lawton Chiles
to
Senate Finance Committee
May 24, 1988

Senator Bentsen and fellow committee members, I am grateful for the opportunity to talk to you about a child health need which in my opinion is the ultimate child health concern in the United States today, i.e. enabling babies to be born healthy.

As you know, I am Chairman of the National Commission to Prevent Infant Mortality, a one-year Commission which is developing a strategy to reduce infant mortality. I have learned a lot this year and would like to share some of my insights with you today.

To put this all in perspective, I want to remind you that 40,000 babies die every year in the United States before their first birthday. That is five babies an hour, every hour, every day. We lose about the same number of babies in one year as all the citizens we lost over the course of the Vietnam war. The deaths are just the tip of the iceberg. For every baby that dies, many more live with physical or emotional disabilities that take their toll both in human and fiscal terms. Many of these innocent victims could be spared their tragedies if we could only re-focus this nation's priorities to better promote the health and wellbeing of children born in this country.

As Chairman of this Commission, one of the most important things I have learned is that we have to change the American mind-set about this problem. It is not that we lack the know-how to have babies born healthy. We know how to do that better than any other nation in the world. What we lack is a sense of priority, of national importance, to the steps that must be taken to assure each baby the best possible start in life.

As I go around the country talking to people about the problem of infant mortality, I have been surprised to find out that they little about it. They "assume" in this great country of ours that mothers and babies are being cared for. After all, this is the USA, home of the Norman Rockwell image of babies being kissed by politicians and pushed on swings in the neighborhood park. If only those images were true! But they are not.

Citizens around the country know about the need for kids to have a good education. They even know a lot about the need for early childhood development and day care. They know about drug abuse and are beginning to know more about AIDS. But by and large they don't know that creating circumstances to help a baby be born healthy can set up a pattern for life that can encourage healthy growth and development for kids.

Our Commission has taken a somewhat unusual approach to the infant mortality problem this year. Instead of spending the year researching the problem, we have taken the position that we know what to do to reduce infant mortality, what we need is to do it. Thus, our hearings have focused on solutions to the problem of infant mortality. We have come up with some interesting answers.

First, we looked to the private sector. What can business and industry and community groups do to advance the cause of healthy mothers, healthy babies? The answer is: A LOT. Whether it is supporting community programs to reduce infant mortality or looking at insurance or leave policies for workers, the private sector has an enormous role to play in promoting the health and wellbeing of children.

Second, we looked to the international community. We were fortunate to hear from individuals from around the world about how they care for their children. It boils down to a matter of priorities. The U.S. now ranks 19th worst among industrialized nations in infant mortality. Many of the countries who do better spend less money overall on their health care and have less advanced medical systems. What they do is place the health of children as a top priority of the nation. And it works.

Third, we looked to the media community. What can radio and television and newspapers and soap operas do to move this issue forward? Again, the answer is: A LOT. The gentleman who produces Cagney and Lacey said he would be willing to consider doing a show about the importance of prenatal care but no-one had approached him before about it. Most responsible journalists will take an issue like this and move it forward if we provide them with the background information they need. We should not shy away from "Madison Avenue" approaches to selling good health. If they can sell almost any product through advertising, then why not use that 'science of selling' to sell health promotion for mothers and infants.

Finally, we looked at the role of government -- federal, state and local. We realized that government can't do it all though it can do a lot with surprisingly few major changes. There is no reason that WIC clinics can't run at the same time as prenatal clinics. There is no reason why a Medicaid form has to be 44 pages long. There is no reason why prenatal services can't be coordinated by case managers. There is no reason to eliminate the White House Conference on Children from our nation's agenda. There is much the government can do right now to improve services to women and children in need.

We will be releasing our final report to the President and Congress some time this summer. It might surprise some people. It will be non-scientific and pragmatic. It will address the crux of the problem: that is, too many babies are dying or are being born handicapped and WE ALL must do something about it to prevent it. Government, business and industry, community groups, doctors, educators, reporters, and the general public all have a role to play.

We will aim to spread caring about mothers and infants from person to person. There is nothing magical about this. It takes commitment and a willingness to want to see children born healthy. It can be done. We need to think about those babies born today as the leaders of our country in the 21st Century. If not, we will pay dearly with a high economic price tag and an even higher humanitarian price tag.

With your leadership, Senator Bentsen, I know these kind of changes can happen. Again, I thank you for the opportunity to speak before you today.

Statement by Senator Dave Durenberger
"America Must Be the Land of Opportunity for Every Child"
May 26, 1988

Mr. Chairman, I want to commend you for this Hearing and for your continued leadership on child health. I especially commend your commitment to ensuring that infants and pregnant women whose family incomes are below the poverty level will be guaranteed access to prenatal, newborn care and delivery services through enactment of the Catastrophic Illness Protection Act.

While we should be very pleased about this improvement in Medicaid, we should not rest until we guarantee that all pregnant women and children have access to the health, nutrition and other child protection services that are essential for the right start in life.

This hearing should help us to identify additional actions that must be taken as soon as humanly possible. Many poor people will be helped by substantially expanding Medicaid--as is happening now in Minnesota where they have taken the option of covering women and infants up to 185% of poverty. But, we must not limit ourselves to Medicaid changes only.

We think of Medicaid and Maternal and Child Health because those are the levers we have. But we need an overall strategy to reduce infant mortality in the country and to produce healthy babies, as we have documented on the Infant Mortality Commission.

We need to create a true safety net of private health plans and public programs to ensure the physical and mental well being of all American children. We must find a way to reach those who may not qualify for Medicaid--perhaps because they have some private health insurance--yet do not have the means or know what they should be doing to ensure having a healthy child.

Programs in Minnesota such as" Good Health is Good Business and "Right Start" are good examples, thanks to the outstanding work of the Children's Defense Fund, the March of Dimes Birth Defects Foundation, and other helping organizations.

We must revolutionize our own thinking about these problems. Every year, we lose another group of children for one reason or another. A year or two in a child's life is a very long time and can mean slower growth, physical, mental or emotional crippling from which he or she may never truly recover.

I believe that every child must be treated as a national treasure. We hear a lot about dependency ratios as we debate the need for taking care of an aging population. We could look on the next 10-20 years as a time when we will have a relatively smaller number of babies per adults.

So we have no excuse for not treating every one of those babies as something precious. The small number of babies relative to the numbers of adults gives us an opportunity for heaping love and attention--to say nothing of needed health care, and a mix of stimulation for learning and opportunities for age-appropriate developmental assistance--on those babies.

It is because of these beliefs that I am sponsoring legislation that would dramatically expand Medicaid and a long list of other health and education programs, including the innovative Smart Start with Senator Kennedy.

But I am certainly not alone in my efforts to reorder our national priorities. What is striking today is how broad is the base of support is for these changes and how many individuals or organizations have examined the state of the nation's educational or health systems and have concluded that action is essential.

An example is recent report from The Committee for Economic Development(CED) , an independent research and educational arm of over two hundred business executives and educators. The CED concluded that of all the demographic issues currently facing the nation, none is as serious as the alarming increase in unmarried teenage parenthood and the attendant poverty and dependency such families usually experience.

Teenage motherhood stunts two lives at once. Girls who have babies at age 15, 16, or even younger frequently become permanent drop-outs from school and society, forever dependent on government support. Children born to teenage mothers face special health risks. They are often born prematurely or suffer from low birth weight, conditions that predispose them to developmental retardation and a variety of learning disabilities.

Other statistics on Teen parenthood highlight the terrible costs of this problem to the individuals involved and to society.

Over 50% of welfare expenditures goes to families in which the mother began her parenting as a teenager.

From 18 to 25 percent of all teenage mothers will become pregnant with their second child within one year of having their first.

The United States has the highest rate of teenage pregnancy among all developed countries--seven times that of the Netherlands, and more than twice that of Great Britain and Canada. Fewer than 50% of teen mothers graduate from high school.

The CED recommends a five-step program, including the provision of prenatal and postnatal health care and nutritional guidance for mothers and babies. Low birth weight leads to health problems and learning disabilities. Every baby must be nurtured, protected and given a healthy start in life. Every baby is a national resource that must be treated well for our own sense of morality and decency, as well as our economic and social well-being.

In addition, given what we know about neglect and abuse, we must institute programs on parenting and child development. We must set up child abuse prevention programs that identify at risk infants early and protect them with educational programs and intervention, if necessary. An excellent example of such a program is found in Ramsey County's Home Health Visitor Program. The program integrates volunteer parent befrienders and professional service providers (such as public health nurses) to prevent maltreatment of children.

We know a growing amount about what causes or is connected with poor health, stunted or twisted emotional health, and subsequent failures and repetitive cycles of dependency, failure to thrive or adjust to society, addiction to drugs and even crime. We must reorder our national priorities. We must set a floor of health care, nutrition and other child protections.

As we stand on the threshold of the twenty-first century the American Dream is in jeopardy. This nation cannot compete and prosper in the global arena when more than one-fifth of our children live in poverty and a third grow up in ignorance.

If we continue to squander the talents of millions of our children, America will become a nation of limited human potential. It would be tragic if we allow this to happen. America must become the land of opportunity--for every child.

Archie S. Golden, M.D.

Good Morning, Mr. Chairman and distinguished members of the panel. My name is Dr. Archie S. Golden. I am a pediatrician and Medical Director of the Chesapeake Health Plan, Chief of Pediatrics at the Francis Scott Key Medical Center and Associate Professor of Pediatrics at the Johns Hopkins University School of Medicine. The Chesapeake Health Plan is a health maintenance organization which contracts with the State of Maryland to provide health care for over 500 foster children in Baltimore City, Maryland. The plan provides for the initial Early Periodic Screening, Diagnosis and Treatment (EPSDT) health appraisal, including psychological assessment, and ongoing health care of the foster children.

I am here today on behalf of the Child Welfare League of America which is a national association of 500 leading public and voluntary non-profit member agencies and 1000 affiliates who provide services to 2.3 million children and their families annually. CWLA agencies provide a range of services, such as, day care, family support, foster family care, group homes, residential treatment, adoption, services to pregnant and parenting teenagers, services to abused and neglected children, children infected with the AIDS virus, and children who are drug or alcohol addicted.

In January 1987, the Child Welfare League of America and the American Academy of Pediatrics, with support from the Hasbro Children's Foundation undertook a series of activities designed to identify and address the major problems within the field of health supervision for children in foster care. For the first phase of the project, the Child Welfare League of America convened a two-day Colloquium, in which twenty leading experts in the United States on health care for foster children participated. The purpose of the Colloquium was to identify the most critical problems related to the health care needs of children in foster care and to recommend solutions. The group was comprised of physicians, social workers, foster parents, health maintenance organization and child welfare administrators, several of whom have conducted research and published extensively on the topic.

My written testimony is based on highlights of the White Paper on the Health Care of Children in Foster Care that resulted from the Colloquium. The White Paper represents the discussion that took place during the Colloquium as well as an overview of the published research on this subject. It has provided a focus for subsequent activities undertaken by the Child Welfare League of America to address this issue, including the development of a training curriculum (which has been tested through the Maryland Department of Human Resources/Social Services Administration) and Standards for the Health Care of Children In Out-of-Home Care (currently in final draft form.)

The most important feature of tne White Paper was the overwhelming consensus among the experts that children in foster care exhibit much higher rates of physical and emotional illness and developmental and emotional problems than non-placed children of the same age. As a group, foster children have certain unique physical, emotional and social health needs because of the very circumstances that bring them to an agency's attention. Histories of abuse or neglect are widespread; many foster children are from chronically poor or minority families -- all sufficient for labeling foster children a high-risk group for health care. (White, Benedict, Jaffe 1987)

For example, in an early study conducted in New York City in 1975, researchers found that over half the pre-school aged foster children had no record of immunization against mumps (68%), about two-fifths were unprotected against measles (36%) and rubella (43%) and close to one-fifth had not been fully immunized against polio (19%) and diptheria, tetanus and pertussis (23%). Of all the foster children studied, 45% had at least one chronic illness. (Swire and Kavaler 1977)

More recent studies have indicated few changes either in the health needs of foster children or the methods of health care delivery and supervision. Similar to Swire and Kavaler, Schor (1982) found that among 378 foster children enrolled in a Baltimore health maintenance organization, more than 45% of all diagnoses reflected chronic conditions many of which were unidentified before enrollment in the HMO. Schor noted that unrealistic expectations of short-term foster care predisposed those responsible for foster children to "postpone important medical interventions" until the children returned home. Further problems identified by Schor were: health care provider and social welfare staff discontinuities as well as the lack of medical records, service coordination and health care funding.

Moreover, despite the existence of EPSDT and Medicaid programs, White and Benedict (1985), examining the health status and utilization patterns of 417 children in foster care in Baltimore, found that EPSDT exams were completed for only 30% of the newly enrolled and 18% of the longer-term children. And, only 11.9% of the newly enrolled children and 11.1% of the longer-term children had received psychological services.

In summary, the problems identified in the White Paper with respect to the provision of health care for children in foster care which require immediate attention include:

- There is no comprehensive adequately organized system of health care available to and designed to meet the health needs of children in foster care.
- Information on the health care of children prior to their entry into the foster care system is often not available nor regularly sought. (A California study (Halfon 1986) noted only one county of the fourteen surveyed, routinely provides for children a mental health examination within 72 hours of placement.)
- Children in foster care are not routinely entitled to health care services under child welfare auspices until responsibility for their care has been formally assumed by the child welfare agency, thus, precluding necessary pre-placement assessments.
- A high proportion of children in foster care have chronic physical and mental health problems which require skilled and often time-consuming professional

care, much of which is not currently reimbursable.

- o Title XIX Medicaid and EPSDT programs currently provide only limited access to the health care services needed by children in foster care.
- o There are no agreed upon standards of quality that can be applied to the health care of foster children.
- o Child welfare agencies rarely have an administrative mechanism in place that adequately monitors the health care provided to the foster children in their care.
- o The collection and management of health information about foster children by child welfare agencies is generally not an organized process and therefore, is usually inadequate for casework use.

Following from these problems, the White Paper suggests a number of recommendations for improving the health status of children in foster care which are summarized below.

1. Children in foster care should have available to them an organized system of health care which includes:

- o A structured and comprehensive intake system that includes a pre-placement health evaluation, comprehensive medical history, a standardized mental health assessment, and a comprehensive health assessment within 30 days of placement.
- o Designated health care providers with expertise in child health and development and knowledge about the foster care system.
- o Continuity of health records, including a centralized medical record and an abbreviated record that remains with the child.
- o Continuity of primary health care providers whenever possible.
- o Comprehensive, continuous and coordinated health care.
- o A schedule of health supervision that includes attention to the special needs of foster children.

2. Child welfare agencies should establish administrative processes to assure high quality health care for foster children in their care which includes, at a minimum:

- o Assignment of responsibility to a centralized unit within the agency for obtaining health information, health care, and for monitoring the quality of health services.
- o A centralized, available and usable health record integrated into each child's case record.
- o Designation of primary health care providers and identification of sources of specialized health care.
- o A quality assurance program which includes a periodic review of agency data on health care and the health care status of foster children.
- o Established lines of communication among all those responsible for aspects of foster children's health care, including the child's biological parents.

3. Child welfare agencies should provide training for foster parents, caseworkers and health care providers regarding the health care of children in foster care.

While many of these recommendations may appear obvious, it is important to point up that to accomplish any one, let alone all, would most likely be an extremely arduous undertaking since, in the majority of states, it requires the ongoing coordination and cooperation of two separate and distinct systems: health and child welfare. There are, however, some states and localities which have or are working toward establishing systems that insure the adequate delivery of health care to children in foster care.

Massachusetts, for example, has Project Good Health (PGH) which is, in fact, its EPSDT program. PGH includes routine medical, dental and mental health services as well as emergency services. There are two key components of this system: (1) every child in placement has a Medical Passport which they carry with them throughout their stay in foster care and for which the child's social worker, foster parents or child caring institution, physician and dentist each have a responsibility for maintaining; and,(2) a "health care tickler report" which is a computer generated report notifying the social worker to schedule a specific type of examination (i.e., medical, dental, mental health/follow-up or routine periodic.)

Following an 18-month study sponsored by the United Way of Los Angeles, the Los Angeles County Department of Children's Services is in the process of implementing a comprehensive health service system for children in foster care which: (1) insures that the Los Angeles County Department of Health Services provides for the health care of foster children; (2) includes a standardized system to maintain and record health care information (i.e., a Medical Passport, similar to the Massachusetts' model); (3) provides training for foster parents, health care providers and state agency staff; and (4) seeks to increase the number of physicians and dentists willing to treat foster children through outreach and recruitment campaigns.

The benefits to foster children of such efforts are clearly reflected in a 1985 study of a foster care agency which found that once the agency developed a clear set of guidelines, staff felt free to carry out comprehensive health care maintenance. The results were: 71% of the children had undergone an examination in the previous year (compared to 52% 3 years earlier); the completed immunization rate had increased from 48% to 73%; and, handicapping or chronic conditions were documented in 26% of the children (as compared to 16% 3 years prior.) (Moffatt, Peddie, Stulginskas, Pless, Steinmetz 1985)

The Senate Finance Committee, having jurisdiction over both the foster care and health systems, is in a unique position to assist in helping to address the inadequacies in each system while ensuring coordination between the two. Specifically, CWLA recommends that the following changes be made by this Committee for purposes of improving health care services to children in foster care:

- Medicaid should be an entitlement for all children in foster care, as payor of last resort.
- Mandated uniform health benefit packages for children in foster care.
- Building on the Medicaid and EPSDT programs, CWLA calls

for stringent application of existing services as well as an expanded schedule of services such as the inclusion of pre-placement assessments and post-discharge care and supervision.

- Increased mental health services.
- Federal oversight with regard to medical record keeping and health care quality assurance programs by child welfare agencies.

With respect to the latter recommendation, there is currently pending in the House of Representatives a bill, H.R. 2753, Section II of which, if passed, would be a move in the right direction. H.R. 2753, introduced by Representative Robert Matsui (D-CA) would require that the case plan of every child in foster care include a health care plan setting forth, at a minimum: a record of when the child received or is scheduled to receive a health examination (including physical and mental health examination); a record of immunizations; known allergies; assurances that periodic examinations will be scheduled as appropriate; a record of health care providers; and assurances that foster parents or child caring institutions have copies of the health care plan and understand their responsibilities in meeting the health care needs of the child.

CWLA strongly urges the introduction and favorable consideration of a Senate companion to H.R. 2753.

Thank you for this opportunity to report to you on the health status of some of our nation's most vulnerable children. The Child Welfare League of America will be pleased to provide you with any additional information regarding their findings and recommendations for the health care of children in out-of-home care.

HOMECARE

STATEMENT OF VAL J. HALAMANDARIS

MR. CHAIRMAN & MEMBERS OF THE COMMITTEE,

I AM VAL J. HALAMANDARIS, PRESIDENT OF THE NATIONAL ASSOCIATION FOR HOME CARE (NAHC), WHICH IS THE LARGEST PROFESSIONAL ORGANIZATION REPRESENTING THE INTERESTS OF HOME HEALTH AGENCIES, HOMEMAKER-HOME HEALTH AIDE ORGANIZATIONS, AND HOSPICES. NAHC IS COMMITTED TO ASSURING THE AVAILABILITY OF HUMANE, COST-EFFECTIVE, HIGH QUALITY HOME CARE SERVICES TO ALL WHO REQUIRE THEM.

I COMMEND YOUR COMMITTEE FOR THIS SERIES OF HEARINGS ON CHILDREN'S HEALTH CARE. THE ISSUE OF CARING FOR CHRONICALLY ILL CHILDREN IS OF GREAT IMPORTANCE TO HOME CARE PROVIDERS.

THERE ARE TEN MILLION CHRONICALLY ILL CHILDREN IN THIS COUNTRY. MANY WOULD NOT BE ALIVE BUT FOR THE ENORMOUS ADVANCES IN MEDICAL TECHNOLOGY IN THE LAST DECADE. MUCH OF THAT TECHNOLOGY IS NOW PORTABLE, ALLOWING FOR THE CARE OF THESE CHRONICALLY ILL CHILDREN IN THEIR OWN HOMES. HOWEVER, FUNDING MECHANISMS HAVE NOT KEPT PACE WITH THE TECHNOLOGY, AND THE RESULT HAS BEEN THAT THOUSANDS OF CHILDREN WHO COULD BE AT HOME HAVE REMAINED IN HOSPITALS.

WE HAVE CONDUCTED RESEARCH ON THE PROBLEMS FACED BY CHRONICALLY ILL CHILDREN AND THEIR FAMILIES, AND I AM PLEASED TO BE ABLE TO SHARE OUR FINDINGS WITH THIS COMMITTEE.

NAHC HAS FOUND THAT TEN TO FIFTEEN PERCENT OF ALL CHILDREN, OR ROUGHLY TEN MILLION YOUNGSTERS, HAVE A CHRONIC ILLNESS. ABOUT TWO MILLION OF THIS NUMBER ARE SEVERELY IMPAIRED.

MANY OF THESE CHILDREN ARE BORN PREMATURE. AS SUCH, THEIR INTERNAL ORGANS OFTEN ARE NOT FULLY DEVELOPED. IN OTHER CASES, THE YOUNGSTERS WERE CARRIED FULL TERM BUT SUFFER FROM CONGENITAL DISABILITIES.

MANY OF THESE CHILDREN FALL INTO ELEVEN CATEGORIES, OR WHAT HAVE

BEEN CALLED "MARKER" DISEASES. THEY ARE: LEUKEMIA, CYSTIC FIBROSIS, CONGENITAL HEART DISEASE, SPINA BIFIDA, ASTHMA, HEMOPHILIA, CHRONIC KIDNEY DISEASE, JUVENILE DIABETES, MUSCULAR DYSTROPHY, CLEFT PALATE, AND SICKLE CELL ANEMIA. A SMALL BUT RAPIDLY GROWING NUMBER ARE CHILDREN WHO ARE VICTIMS OF AIDS.

MANY OF THESE YOUNGSTERS LIVE IN PEDIATRIC INTENSIVE CARE UNITS OF THE NATION'S HOSPITALS, AND A LESSER NUMBER ARE IN NURSING HOMES. THEY ARE SOMETIMES CALLED "MILLION DOLLAR BABIES" BECAUSE THE COST OF THEIR CARE MAY EXCEED $1 MILLION DOLLARS A YEAR.

THE CHILDREN ARE ALSO KNOWN AS "TECHNOLOGY DEPENDENT," A REFERENCE TO THE FACT THAT THEY OWE THEIR VERY LIVES TO MODERN TECHNOLOGY AND CONTINUE TO BE DEPENDENT UPON IT TO SOME EXTENT. IT IS THE EVOLUTION AND REFINEMENT OF SUCH TECHNOLOGY WHICH MAKE IT POSSIBLE FOR THESE SPECIAL CHILDREN TO BE CARED FOR AT HOME.

MUCH NEW TECHNOLOGY, WHICH WAS ONCE AVAILABLE ONLY IN A HOSPITAL, HAS BEEN MADE SMALLER, MORE PORTABLE AND EVEN ADAPTED FOR BATTERY POWER. NEW TREATMENT MODALITIES ALSO ALLOW THESE CHILDREN TO BE CARED FOR AT HOME RATHER THAN IN AN INSTITUTION.

ONE EXAMPLE OF THIS NEW TECHNOLOGY IS: INTRAVENOUS CHEMOTHERAPY, THE INFUSION OF CANCER FIGHTING DRUGS INTO THE BLOOD STREAM, WHICH IS NOW ROUTINELY DONE AT HOME. STUDIES INDICATE THAT THE PROCEDURE IS NOT ONLY LESS STRESSFUL FOR THE PATIENT, BUT ALSO PRODUCES BETTER THERAPEUTIC RESULTS AND MINIMIZES SIDE EFFECTS.

ANOTHER EXAMPLE IS TOTAL PARENTERAL NUTRITION (TPN), WHICH INVOLVES INTRAVENOUS FEEDING OF A CHILD WHO OTHERWISE CANNOT EAT. KIDNEY PATIENTS CAN ALSO RECEIVE DIALYSIS AT HOME. HEART PATIENTS CAN REMAIN AT HOME WHILE BEING WATCHED BY MEANS OF CARDIAC MONITORS AND TESTED WITH PORTABLE ELECTROCARDIOGRAM UNITS.

CHILDREN WHO ARE IN DANGER OF DYING BECAUSE OF SUDDEN INFANT DEATH SYNDROME (SIDS) CAN NOW BE GUARDED BY MEANS OF MACHINES CALLED APNEA MONITORS. THE MACHINES TRIGGER AN ALARM IF THE

CHILD'S BREATHING SLOWS SIGNIFICANTLY AND/OR IF THE CHILD GOES INTO RESPIRATORY ARREST.

MOST IMPRESSIVE OF ALL, CHILDREN WHO DEPEND ON AN ARTIFICIAL DEVICE CALLED A VENTILATOR TO DO THEIR BREATHING FOR THEM CAN, AND ARE, BEING SENT HOME. SOME VENTILATORS ARE SMALL ENOUGH THAT THEY CAN BE PLACED ON THE BACK OF A WHEELCHAIR, FOLLOWING THE CHILD WHENEVER HE OR SHE MIGHT WANT TO GO.

PHYSICIANS ARE IN AGREEMENT THAT IT IS POSSIBLE TO MANAGE THE CARE OF MOST CHILDREN AT HOME--EVEN COMPLEX CASES INVOLVING MULTIPLE DISABILITIES. PHYSICIANS ARE IN GENERAL AGREEMENT AS TO THE CRITERIA WHICH MUST BE MET BEFORE A CHILD CAN BE DISCHARGED FROM AN INSTITUTION INTO A HOME CARE SETTING. FIRST, THE CHILD MUST BE MEDICALLY STABLE. SECOND, THE TRANSFER TO THE HOME MUST OFFER THE CHILD AN IMPROVED QUALITY OF LIFE. THIRD, THE TRANSFER TO THE HOME SETTING MUST BE AN ACCEPTABLE RISK. THE RISKS MUST BE SMALL ENOUGH TO BE OFFSET BY THE ADVANTAGES OF HAVING THE CHILD AT HOME. FOURTH, THE FAMILY MUST BE WILLING AND ABLE TO TAKE ON MOST OF THE CHILD'S CARE. FIFTH, THERE MUST BE ADEQUATE COMMUNITY SUPPORT AVAILABLE. THE MOST IMPORTANT FACTOR IN ALL OF THE ABOVE IS NUMBER FOUR.

PARENTS NEED HELP, TRAINING, AND SUPPORT IF THEY ARE GOING TO SUCCESSFULLY CARE FOR THEIR CHRONICALLY ILL CHILDREN AT HOME. RESPITE CARE IS NOT A LUXURY, BUT A NECESSITY. SOMEONE MUST GIVE THE PARENTS SOME RELIEF FROM THE HEAVY BURDEN OF WATCHING OVER THE CHILD TWENTY-FOUR HOURS A DAY. WHILE PARENTS CAN BE TRAINED TO PERFORM MANY PROCEDURES, OTHERS MUST BE PERFORMED ONLY BY LICENSED NURSES IN CONFORMITY WITH STATE LAWS AND THE BEST INTERESTS OF THE CHILD.

PROLONGED HOSPITAL STAYS POSE SIGNIFICANT PROBLEMS FOR CHILDREN. SPECIFICALLY, THEIR DEVELOPMENT IS STUNTED, BONDING BETWEEN THEM AND THEIR PARENTS IS INHIBITED, THE CHILD IS DEPRIVED OF FREEDOM AND PLACED IN AN ENVIRONMENT WHICH, FOR ALL ITS LIFE-SAVING POTENTIAL, IS MORE DANGEROUS TO THE CHILD, AND

SIGNIFICANT STRESS IS PRODUCED BY THE VERY FACT THAT THE CHILD IS IN THE HOSPITAL.

ON THE OPPOSITE SIDE OF THE COIN, CARE OF THE CHILD AT HOME BY HIS OR HER PARENTS WITH REQUISITE SUPPORT HAS OVERWHELMING ADVANTAGES. IT IS BETTER FOR THE CHILD AND AIDS HIS OR HER DEVELOPMENT. IT ALSO KEEPS FAMILIES TOGETHER, REDUCES STRESS, PROVIDES THE CHILD WITH FREEDOM AND THE OPPORTUNITY TO LIVE THE HIGHEST QUALITY LIFE, AND IS MORE COST EFFECTIVE.

BRINGING THEIR CHILD HOME IS THE HAPPIEST DAY FOR MOST PARENTS OF CHRONICALLY ILL CHILDREN. THE GREATEST OBSTACLE STANDING IN THE WAY OF BRINGING THOSE CHILDREN HOME IS THE LACK OF FUNDING FOR THEIR CARE AT HOME.

MEDICARE, MEDICAID, CRIPPLED CHILDREN'S SERVICES, CHAMPUS AND OTHER GOVERNMENT PROGRAMS PROVIDE VERY LITTLE, IF ANY, HELP AND HAVE A BIAS IN FAVOR OF INSTITUTIONALIZATION. PRIVATE HEALTH INSURANCE IS ALSO INADEQUATE AND SUFFERS FROM THE SAME BIAS.

MANY PARENTS ARE FORCED TO QUIT THEIR JOBS AND MOVE FROM ONE STATE TO ANOTHER, LOOKING IN VAIN FOR SOME STATE WITH A MORE COMPREHENSIVE AND HUMANE POLICY WHICH WILL ALLOW THEM TO CARE FOR THEIR CHILD AT HOME. SOME FAMILIES ARE FORCED TO LITERALLY GIVE UP THEIR BABIES, TO HAVE THEM BECOME WARDS OF THE STATE, IN ORDER THAT THEY MIGHT RECEIVE THE CARE THAT THEY NEED.

THIS LACK OF A MEANINGFUL POLICY CAUSES FAMILIES TO MAKE A HOBSON'S CHOICE. THEY CAN EITHER LEAVE THEIR CHILD IN THE HOSPITAL FOR MONTHS OR YEARS AT A TIME SO THAT CARE WILL BE REIMBURSED, OR THEY CAN BRING THEIR CHILD HOME, KNOWING THERE IS LITTLE, IF ANY REIMBURSEMENT AVAILABLE.

CARE IN THE HOME IS ALMOST ALWAYS MUCH LESS EXPENSIVE THAN COMPARABLE CARE IN THE HOSPITAL. HOME CARE ENJOYS THE COST BENEFIT BY MARGINS AS HIGH AS EIGHTEEN TO ONE OVER HOSPITAL CARE. IT IS QUITE COMMON FOR HOME CARE TO COST ONLY ONE-TENTH THE COST

OF COMPARABLE CARE IN THE HOSPITAL. MOST ACTUAL EXPERIENCE AND MOST STUDIES INDICATE THAT HOME CARE COSTS AVERAGE ONLY ABOUT ONE-FOURTH OR ONE-FIFTH OF THE COST OF CARE IN THE HOSPITAL.

ONE INSURANCE COMPANY, AETNA LIFE AND CASUALTY, HAS SEEN THE WISDOM AND ADVANTAGES OF HOME-BASED CARE AND HAS DEVELOPED WHAT IT CALLS ITS INDIVIDUAL CASE MANAGEMENT (ICM) PROGRAM. AETNA REPORTED SAVINGS OF $36 MILLION IN 1985 THROUGH USE OF THE ICM PROGRAM. THE SAVINGS WERE POSSIBLE IN PART THROUGH IMPLEMENTATION OF THE PARENTS' WISHES TO BRING THEIR CHILDREN HOME FROM THE HOSPITAL.

THAT SERVICE COORDINATION OR CASE MANAGEMENT COMPONENT IS VERY IMPORTANT TO THE SUCCESS OF A PEDIATRIC HOME CARE PROGRAM, BECAUSE SOMEONE MUST TAKE RESPONSIBILITY FOR COORDINATING ALL THE SERVICES AND CARE THAT CHRONICALLY ILL CHILDREN NEED.

IT IS BETTER FOR THEM, BETTER FOR THEIR FAMILIES, AND BETTER FOR THE NATION. WITH HELP, MANY OF THESE CHILDREN WILL OUTGROW THEIR AILMENTS. WITH ASSISTANCE, MOST OF THEM WILL DEVELOP TO THE FULL EXTENT OF THEIR ABILITIES AND HAVE A REASONABLE OPPORTUNITY TO LEAD MEANINGFUL LIVES AND TO CONTRIBUTE TO SOCIETY.

NAHC OFFERS THESE RECOMMENDATIONS FOR YOUR CONSIDERATION:

CRIPPLED CHILDREN'S SERVICES

THE PRINCIPAL FLAW IN OUR CURRENT NATIONAL HEALTH POLICY AS IT IMPACTS ON CHRONICALLY ILL OR SEVERELY DISABLED CHILDREN IS THE LACK OF A COMPREHENSIVE PROGRAM OF CARE AT HOME. AS DISCUSSED BELOW, MEDICARE IS LARGELY INAPPLICABLE TO THIS PEDIATRIC POPULATION. MEDICAID, THE MAJOR SOURCE OF GOVERNMENT DOLLARS, SUFFERS BOTH FROM INADEQUATE COVERAGE AND FROM FRAGMENATION AT THE STATE LEVEL.

THE INADEQUACY OF COVERAGE IS EASILY DOCUMENTED. THE TOTAL OUTLAYS OF THE MEDICAID PROGRAM IN 1985 WERE ABOUT $38 BILLION.

THE LION'S SHARE OF THIS MONEY -- MORE THAN FORTY PERCENT OF IT -- WENT TO PAY FOR NURSING HOME CARE. FUNDING TO HELP CARE FOR PATIENTS IN THEIR OWN HOMES, BY CONTRACT, AMOUNTED TO ONLY $1.1 BILLION, OR JUST SLIGHTLY LESS THAN THREE PERCENT OF THE ENTIRE PROGRAM. AND OF COURSE, NOT ALL OF EVEN THIS MINIMAL ALLOTMENT WENT TO SERVE CHRONICALLY ILL CHILDREN.

OBVIOUSLY, MEDICAID SUFFERS FROM AN INSTITUTIONAL BIAS, DESPITE THE FACT THAT EVIDENCE FROM THE U.S. GENERAL ACCOUNTING OFFICE AND OTHER SOURCES INDICATE THAT A SIGNIFICANT PROPORTION OF INSTITUTIONAL PATIENTS DO NOT BELONG IN A NURSING HOME AND COULD BE CARED FOR AT HOME. WHAT IS MORE SIGNIFICANT IS THAT MOST OF THE PAYMENTS FOR HOME CARE UNDER MEDICAID WERE IN ONE STATE, NEW YORK. THAT STATE'S "NURSING HOMES WITHOUT WALLS" PROGRAM, WHICH PROVIDES THE HOME CARE ALTERNATIVE TO CAREFULLY SCREENED PATIENTS WHO WOULD OTHERWISE BE IN NURSING HOMES, HAS ENABLED NEW YORK TO SAVE AN ESTIMATED FIFTY PERCENT OF THE EXPENDITURES IT WOULD HAVE MADE FOR NURSING HOME CARE FOR ITS NURSING-HOME-WITHOUT-WALLS PATIENTS.

ASIDE FROM NEW YORK, THE RESOURCES CURRENTLY BEING MADE AVAILABLE TO HOME CARE PATIENTS GENERALLY AND PEDIATRIC HOME CARE PATIENTS IN PARTICULAR ARE INDEED MINISCULE. IN ADDITION, BECAUSE MANY OF THE COVERAGE AND ELIGIBILITY CRITERIA FOR PEDIATRIC HOME CARE SERVICES ARE CURRENTLY LEFT TO THE STATES, THERE IS WIDE VARIATION IN AVAILABILITY. IN AT LEAST ONE STATE, ARIZONA, PARENTS ARE EVEN FACED WITH THE POSSIBILITY OF HAVING TO MAKE THEIR CHILD A WARD OF THE STATE IN ORDER TO SECURE COVERAGE.

FOR THESE REASONS, NAHC RECOMMENDS THAT THE CRIPPLED CHILDREN'S SERVICES COMPONENT OF TITLE V OF THE SOCIAL SECURITY ACT, THE MATERNAL AND CHILD HEALTH SERVICES BLOCK GRANT, BE EXPANDED TO PROVIDE A COMPLETE AND ORGANIZED PROGRAM FOCUSING ON THE PEDIATRIC HOME HEALTH CARE ALTERNATIVE. WHILE STATES WOULD MAINTAIN SOME RESPONSIBILITY FOR DIRECTING AVAILABLE FUNDS TO APPROPRIATE RECIPIENTS AND FOR OVERSEEING THE PROVISION OF SERVICES, THE FEDERAL GOVERNMENT WOULD ESTABLISH UNIFORM

ELIGIBILITY STANDARDS. THE FEDERAL GOVERNMENT WOULD ALSO MANDATE COVERED MEDICAL AND SUPPORT SERVICES, INCLUDING ADEQUATE RESPITE CARE, TO ENABLE THE FAMILIES OF MEDICALLY FRAGILE CHILDREN TO COPE WITH THE STRESS ASSOCIATED WITH THEIR CAREGIVER ROLES.

CHAMPUS

CHAMPUS IS THE FEDERAL PROGRAM WHICH PAYS FOR HEALTH CARE FOR MEMBERS OF OUR ARMED FORCES AND THEIR FAMILIES. OF ALL THE PUBLIC PROGRAMS, CHAMPUS RECEIVED THE WORST MARKS FROM FAMILIES OF CHRONICALLY ILL CHILDREN. ITS LIMITATION OF $1,000 A MONTH FOR HOME CARE IS TOTALLY INADEQUATE TO MEET THE NEEDS OF TECHNOLOGY DEPENDENT CHILDREN. THIS FORCES MORE COSTLY AND LESS HNUMANE INSTITUTIONLIZATION.

CONGRESS COULD PROVIDE A SIGNIFICANT BENEFIT TO THE MEMBERS OF THE ARMED FORCES AND THEIR DEPENDENTS AND RECOUP SIGNIFICANT SAVINGS BY REVISING THIS ANTIQUATED POLICY.

HOSPICE

THE CONGRESS SHOULD ENACT A NATIONAL PROGRAM WHICH PROVIDES HOSPICE CARE FOR CHILDREN. HOSPICE COVERAGE IS PRESENTLY PROVIDED FOR THE ELDERLY UNDER MEDICARE, BUT NO COUNTERPART FOR CHILDREN EXISTS.

MEDICARE

AS TECHNOLOGY EXTENDS THE LIVES OF MEDICALLY FRAGILE INDIVIDUALS, WE NEED TO MAKE PROVISIONS TO ENSURE THEIR CONTINUED WELL-BEING WHEN THEY REACH ADULTHOOD.

MEDICARE'S DEFINITION OF DISABILITY IS UNDULY RESTRICTIVE IN ITS PRESENT APPLICATION. AS A RESULT, VIRTUALLY NO CHILDREN UNDER THE AGE OF EIGHTEEN QUALIFY FOR BENEFITS. BENEFITS FOR THOSE OVER AGE EIGHTEEN ARE ALSO LIMITED TO SHORT TERM, OR SO-CALLED ACUTE, CARE. MEDICARE COVERAGE IS FURTHER RESTRICTED BY TERMS WHICH LIMIT ACCESS TO HOME CARE TO THOSE WHO ARE IN NEED OF INTENSIVE SERVICES (SKILLED NURSING CARE) AND YET NOT ILL TO THE POINT WHERE THEY REQUIRE ASSISTANCE ON A MORE THAN INTERMITTENT BASIS. BENEFITS ARE STILL FURTHER LIMITED IN THAT THEY ARE ONLY AVAILABLE TO THOSE CONFINED TO THEIR OWN HOMES AND TO THOSE WHOSE CARE IS DEEMED REASONABLE AND NECESSARY FOR PARTICULAR CONDITIONS.

NAHC RECOMMENDS THAT THE MEDICARE BENEFIT BE STREAMLINED SO THAT IT PROVIDES COVERAGE FOR HOME CARE SERVICES FOR CHRONICALLY ILL INDIVIDUALS. THE ELIMINATION OF THE IMPEDIMENTS DESCRIBED ABOVE WOULD BE A MAJOR STEP FORWARD IN THE ENACTMENT OF CATASTROPHIC HEALTH PROTECTIONS FOR THE ELDERLY. IT WOULD ALSO PREVENT THE NEEDLESS INSTITUTIONALIZATION OF THOUSANDS OF CHILDREN AND ADULTS.

AS WITH EXPANSION OF THE HOME CARE PROGRAM FOR CHRONICALLY ILL CHILDREN UNDER TITLE V, ANY COMPREHENSIVE PROGRAM UNDER MEDICARE MUST INCLUDE RESPITE CARE SERVICES.

PRIVATE HEALTH INSURANCE

THE CONGRESS SHOULD ENACT LEGISLATION WHICH PROVIDES HEALTH INSURANCE COMPANIES WITH FAVORABLE TAX TREATMENT FOR RESERVES ASSIGNED TO COMPREHENSIVE PRIVATE HEALTH INSURANCE PLANS THAT PROVIDE EXEMPLARY HOME CARE COVERAGE FOR CHRONICALLY ILL CHILDREN.

HEALTH INSURANCE COMPANIES SHOULD EXAMINE THEIR COMPREHENSIVE HEALTH INSURANCE PLANS AND ELIMINATE ANY EXISTING INSTITUTIONAL BIAS. THE FOCUS OF COVERAGE SHOULD BE THE CARE THAT IS NEEDED, NOT THE LOCATION OF THE CARE.

SIMILARLY, UNION AND EMPLOYER-BASED HEALTH INSURANCE PLANS SHOULD BE PURGED OF INSTITUTIONAL BIAS, AND EXPANDED TO COVER HOME CARE SERVICES.

AT A MINIMUM, INSURANCE COMPANIES SHOULD BE ENCOURAGED TO FOLLOW THE EXAMPLE OF AETNA LIFE AND CASUALTY AND CREATE PROGRAMS SIMILAR TO THAT COMPANY'S INDIVIDUAL CASE MANAGEMENT PROGRAM.

EDUCATING MEDICAL PROFESSIONALS

THE FEDERAL GOVERNMENT SHOULD INCREASE THE FUNDING AVAILABLE FOR TRAINING OF MEDICAL PERSONNEL IN THE SPECIAL NEEDS OF CHRONICALLY ILL CHILDREN, THUS FACILITATING THEIR CARE AT HOME.

SCHOOLS OF MEDICINE AND NURSING SHOULD INCREASE THEIR EDUCATIONAL PROGRAMS AT BOTH THE UNDERGRADUATE AND THE GRADUATE LEVEL TO PLACE GREATER EMPHASIS ON THE NEEDS OF CHRONICALLY ILL CHILDREN. THESE PROGRAMS MUST GIVE MEDICAL PROFESSIONALS A THOROUGH GROUNDING IN THE DEVELOPING TECHNOLOGY AND THE SPECIAL PRESSURES AND PROBLEMS OF FAMILIES WHO STRUGGLE TO CARE FOR TECHNOLOGY DEPENDENT CHILDREN.

CONTINUING EDUCATION PROGRAMS SHOULD ALSO BE ESTABLISHED TO HELP UPDATE THE PRACTITIONERS AFTER THEIR GRADUATION.

THE NEED TO EDUCATE THE PUBLIC

FAMILIES OF CHRONICALLY ILL CHILDREN HAVE A DIFFICULT TIME FINDING OUT ABOUT BENEFITS AND LIMITATIONS ON COVERAGE OF HOME CARE.

NAHC RECOMMENDS THEREFORE, THAT THE DEPARTMENT OF HEALTH AND HUMAN SERVICES DEVELOP A PUBLIC INFORMATION CAMPAIGN AND OTHER OUTREACH MECHANISMS TO HELP EDUCATE THE PUBLIC ABOUT EXISTING PROGRAMS AND ABOUT HOW TO CARE FOR TECHNOLOGY DEPENDENT CHILDREN.

RESEARCH

GIVEN THE STEADY INCREASE IN THE NUMBER AND PERCENTAGES OF CHRONICALLY ILL CHILDREN, THE FEDERAL GOVERNMENT SHOULD INCREASE

RESEARCH TO IDENTIFY THE CAUSE AND POSSIBLE CURE FOR THE ELEVEN SO-CALLED MARKER DISEASES DISCUSSED EARLIER.

EDUCATIONAL PROGRAMS

THE FEDERAL GOVERNMENT SHOULD INCREASE FOR PROGRAMS WHICH PROVIDE EDUCATIONAL OPPORTUNITIES FOR CHRONICALLY ILL OR TECHNOLOGY DEPENDENT CHILDREN.

S.1616/H.R.3436

CONGRESSMAN CLAUDE PEPPER AND SENATOR PAUL SIMON HAVE INTRODUCED LEGISLATION (H.R. 2762/S.1616) WHICH WOULD CREATE A NEW MEDICARE LONG TERM CARE HOME CARE BENEFIT. IN ADDITION TO PROVIDING LONG TERM HOME CARE FOR ELDERLY AND DISABLED INDIVIDUALS THIS LEGISLATION WOULD COVER CHRONICAL ILL AND TECHNOLOGY DEPENDENT CHILDREN. NAHC SUPPORTS THIS LEGISLATION AND URGES THIS COMMITTEE'S SERIOUS CONSIDERATION OF THE BILL.

MR. CHAIRMAN, I APPRECIATE THE OPPORTUNITY TO DISCUSS THESE IMPORTANT ISSUES WITH YOU. I WILL BE HAPPY TO RESPOND TO ANY QUESTIONS YOU MAY HAVE.

Good Morning. I am Alfred Healy, M.D., professor of pediatrics at the University of Iowa. I am pleased to be here today on behalf of the American Academy of Pediatrics, the American Pediatric Society, the Society for Pediatric Research and the Consortium for Citizens with Developmental Disabilities Task Force on Health and Children. The Academy represents over 34,000 pediatricians dedicated to improving the health and welfare of our nation's infants, children and adolescents. The CCDD consists of virtually every national disability organization concerned with policy on behalf of persons with disabilities including consumers, providers and professional agenies.

At the outset Mr. Chairman, I want to commend you and your committee for your tireless advocacy on behalf of children. Despite the specter of punishing deficits, through your leadership, this committee has successfully fashioned significant improvements in the Medicaid program for mothers and children each year since 1983. This committee is also responsible for creating the Maternal and Child Health Block Grant and has advocated important reforms to many other child health programs in the past.

Nevertheless, despite your best efforts and those of your colleagues, there remains more promise than progress in these vital programs.

o By 1984 Medicaid reached only 38 percent of the poor, down from 65 percent a decade before. This drop followed 12 years of rising enrollments since the program's creation in 1965. Overall enrollment in Medicaid has declined in recent years from a high of 23 million recipients in 1977 to 21.1 million in 1984.

o The rate of children who are uninsured in this country is rising. It is currently estimated that between 11 and 16 million children through age 21 are uninsured all or at least part of the year. The recent OTA report "Healthy Children: Investing in the Future" states, "In 1980, the percentage of children under age 13 who were reported to be uninsured was 17%; by 1984 the rate has increased to 18%; and by 1986, it was 19%. 61% of all children under age 13 who were reported to be uninsured were from either poor or near poor families. Thus, in spite of recently enacted Medicaid expansions available to the states targeted to poor children in younger ages, lack of financial access to the health care system has actually increased rather than leveled off or decreased.

o The infant mortality rate in this country - the accepted benchmark of a nation's child health status - is increasing. Indeed, little progress has been made in recent years to reduce the United States infant mortality rate which continues to rank 17th among industrialized nations behind East Germany, France, Ireland and

Spain. 40,000 infants die each year in the United State before their first birthday (more than 1 percent of all babies born in this country). Many of these deaths could have been prevented by receiving adequate prenatal care, which is the single most important factor in preventing infant mortality. 81% of privately insured women received prenatal care, compared with only 31% of those on Medicaid. Although a number of reasons are cited why women fail to receive prenatal care, lack of medical insurance and physicians who will not accept Medicaid patients are among those most often cited.

- The teen age pregnancy rate in this country is one of the highest in the world and is rising. US girls under 15 years of age are five times more likely to give birth than in other developed countries. Most pregnancies among teens are unintended and infants born to these mothers are at greatly increased risk.

Although the relationship between the lack of financial access to the system and health status is unclear, there is unambiguous evidence that mothers and children without health insurance do not use preventive, chronic and acute care as much an insured children (Rand Health Insurance Experiment). Thus, while a number of factors impact children's access to care, financial barriers are the most significant.

Mr. Chairman, you, I, the members of this committee, the Academy, other child advocacy groups represented by this testimony and those not present, are all responsible for the state of the health of our nation's children and the inequities in the system.

Many of us have appeared before this committee and similar forums in the past. On each occasion, we dutifully review the statistics and present a series of legislative recommendations. Indeed, we probably could have resurrected much of that testimony for our presentation today. After each, you and the other dedicated members of this body try to enact those proposals which are good policy, feasible, and in the current climate, cost effective. But our carefully written statements, lofty rhetoric and good intentions aside, it is time to realize this approach is not working. After a decade of incrementalism, the state of our children's health has not improved commensurate with our resources, and our children's health care system is as fragmented as ever. Nor should we be surprised by this reality. Given that there is no inherent design or "system" of child health care financing in this country, efforts to weave together a coherent plan from the patchwork of programs have failed. Further, if past experience teaches us anything, it is unlikely that these problems will be resolved in the foreseeable future if we pursue current strategies. The enormous variations state by state in the Medicaid program -- which are inherent to its design -- make the program virtually ineffective for many children. Even with a strong federal mandate, it is unlikely that employer -based insurance programs will ever appropriately cover the panoply of services required by children and families with special needs, an ever-growing portion of our population. In short, incrementalism is a failure and our children deserve better.

I am pleased to tell you, Mr. Chairman, that at its recent Executive Board meeting, the Academy voted to invest the time, resources and energy necessary to develop a proposal which would guarantee access to health care for all pregnant women and children. Although the specifics of such a proposal are far from being developed, the underlying principles of such a proposal are clear: that all children must have access to an array of health care benefits that will ensure their optimal health and well being; that these services should be performed in a cost effective manner that does not compromise the highest quality of care; and that these plans should be incorporated as part of a children's health policy.

The Academy plans to work closely with many of the advocates who are represented here today and keep you and your staff informed of our deliberations as we proceed. In the interim, we believe it is important to continue to support and to promote reforms to the existing child health programs, such as Medicaid and the Maternal and Child Health Block Grant, which may serve as the foundation for future efforts. The following testimony thus reviews children's access to care, including children with chronic illness and disability and catastrophic expenses and proposes specific recommendations for Medicaid and Maternal and Child Health Block Grant.

I. CHILDREN'S ACCESS TO CARE

The introduction to the Academy's report on the value of preventive care states:

> "Growth and development are the dynamic processes which distinguish children from adults and dictate periodic, continuing, individual preventive health care to assure that each person may achieve his or her optimum potential."

As such, children have a great need for primary care services and health supervision, including ambulatory care, preventive care and immunizations. Such care supports children and helps them to achieve optimal physical, intellectual and emotional growth and development and improves their chances to develop into healthy and productive adults. Early intervention can prevent disease and minimize the severity of certain disabilities.

Numerous studies have shown that preventive health care at an early age reduces the risk of acute illnesses in later years, which translates to fewer dollars spent on sickness services during an individual's lifetime. It has been found that children screened through EPSDT in Missouri were, on average, 33 percent less costly to Medicaid than other children; in Ohio 30 percent less costly; in North Dakota 40 percent less costly; and so forth. It is ironic that while Medicaid pays for such care, most private health insurance does not. Indeed, the total cost for providing all child health supervision services is less then the cost of one day in the hospital. A 1983 study conducted by the Academy with an independent certified actuary and a major life insurance company showed that the cost for additional coverage according to the Academy's Guidelines for Health Supervision would, on average, be $2.28 per month per family, assuming a 100% utilization rate.

Clearly the cost of children's health care remains a spectacular bargain when compared with that for other age groups, particularly when one considers the number of years of improved functioning that can be bought at such a small price.

In spite of this evidence, most insurance companies discriminate against children by denying coverage for services they need and use, e.g.

ambulatory and preventive services. Children are hospitalized with 1/4 the frequency of adults, but instead use 2.5 times the ambulatory services, particulary when they are young. Children's health expenses are low, approximately $500 per capita year (under 17 years) compared with $1,485 per capita year (ages 45-64) and $2,721 for persons 65 and older. (These numbers are based on 1980 NMCUES data updated for 1984 dollars.) With the exception of HMOs and some group practices, most insurors reimburse for hospitalization for acute care. As such most children are uninsured or or inadequately insured.

POPULATION IN NEED - UNINSURED AND UNDERINSURED

Children as a group are disproportionately uninsured. Nearly one American child in five has no coverage and one third of the uninsured are children. The chance of being uninsured is 37 percent higher for a child than an adult. To put these numbers into context, there are approximately 37 million uninsured individuals of whom:

- 65 percent were employed workers and their dependents (24.3 million);
- 32 percent (11 million) were children age 18 or under;

Of the uninsured children, 64 percent (7 million) lived in a family headed by someone who was also uninsured while 29 percent (3.2 million) lived in a family with employer-based insurance coverage.

National Medical Care Utilization and Expenditure Survey (NMCUES) data from 1980 suggest that an additional 7 million children are only insured for part of the year. Gaps in coverage are particularly large for children between the ages of 0 and 2 years of age, and for adolescents and young adults. Thus, while children represent only 29 percent of the population, they represent, at times, almost half of the uninsured. Children from poor or near poor families (between 100 percent and 150 percent of Federal poverty guidelines) were less likely to have health coverage than their more affluent counterparts. Roughly one third of all poor children under age 13 are uninsured, according to the recent OTA analysis of census data.

These data concern us because the lack of insurance is denying access to medically necessary care, including preventive services recommended by public health agencies, for many children. Numerous studies have shown that uninsured children are far less likely to seek medical care - even when sick - than those who are insured. These children are frequently denied access to care and a larger portion of their expenditures for health care must be spent out of pocket. Further, because they do not receive preventive care and routine health supervisions, they are more likely to incur catastrophic expenses -- in relative as well as absolute terms.

Another NMCUES analysis shows that among low-income children, those without Medicaid were 33 percent more likely not to visit a physician compared with those with Medicaid coverage. Those low-income children without any Medicaid coverage who also had no private insurance coverage were 50 percent more likely to have no medical visits. The analysis also shows that low-income children with Medicaid or private health insurance were likely to see a physician more frequently than those without such coverage. For example, the average number of visits per year for low-income children covered by Medicaid, 2.9 per child, exceeded the average for uninsured low-income children, 1.8 per child.

Even children with health insurance may not be adequately covered for primary care services. Many plans limit benefits, including preventive care, and limit the amount, duration and scope of benefits. Inadequacies in coverage are particulary true for children covered through Medicaid -- where differences in covered services as well as the amount, duration and scope of coverage vary dramatically state by state. Roughly one half of all poor children are covered by Medicaid. Of the 12.9 million children estimated to be in poverty in 1986, 6.7 million were covered through Medicaid.

II. CHILDREN WITH CHRONIC ILLNESS AND DEVELOPMENTAL DISABILITIES AND THOSE WHO INCUR CATASTROPHIC HEALTH EXPENSES

Financing health care for children with special needs is as complex as the health problems of these children. Yet, developmental disability and chronic illness are growing problems among children and adolescents and their health care utilization and expenditures have increased accordingly. Children with disabilities are twice as likely to be hospitalized and spend four times as many days in the hospital as nondisabled children. Disabled children visit physicians five times more than nondisabled children and use six times as many allied health services and twice as many medications. Although major national health financing programs exist for very low-income persons (Medicaid) and for the elderly (Medicare), there is no comparable national program or commitment to children with special health care needs.

Recent prevalence estimates suggest that at least 10 to 15 percent of all U.S. children suffer from a chronic health impairment of varying severity (Gortmaker and Sappenfield, 1984). Most of these children have mild conditions which interfere to only a limited degree with their usual daily activities. Nevertheless, 2 to 4 percent of all children currently face severe chronic health conditions that create special challenges to the family and burdens for the child as he or she grows up. During the last two decades, the number of children with activity limitations has nearly doubled (Newacheck et al, 1986). Researchers believe this increase is the result of improved survival as well as increasing identification resulting from enhanced awareness of chronic illness and disability as important health problems. Recent data show, in fact, that 80 percent of children with the most common severe chronic conditions (e.g., cystic fibrosis, spina bifida, diabetes, congenital heart conditions, cancer, and muscular dystrophy) now live to adulthood. (Hobbs, Perrin and Ireys, 1985)

A subset of children incur catastrophic health expenses, defined as a child whose family's out-of-pocket medical care costs reach a maximum of 10 percent of their annual adjusted gross income. For children who live in families with incomes less than the federal poverty line (one in five), the out-of-pocket threshold should be less than 10 percent, as a smaller proportion of family income for medical care could create catastrophic circumstances for their families. This also includes infants who require neonatal intensive care and children who incur catastrophic expense because of accidents or injury.

All available empirical evidence indicates that the incidence of children in need of financing for catastrophic health care to supplement existing private and public insurance is relatively small in absolute terms and proportionately much lower than that of the adult population. According to the National Medical Care Utilization and Expenditure survey, of the 70 million children in this country, only 0.6 percent (421,000) had out-of-pocket medical expenses greater than 10 percent of their family's income in 1980.

Children (and families of children) with developmental disability and chronic illness and those who incur catastrophic expense have common interrelated psychosocial, medical and educational needs which go beyond those experienced by healthy children or those with acute illness. Some service needs relate to the specific nature of the child's health condition; most, however, reflect the fact that severe chronic illness or disability of any type creates special needs for the child and family (Pless and Perrin, 1985). Additional health-related needs may include more frequent and higher-intensity use of specialty and primary care medical services; services from related allied health professionals (such as physical, occupational, speech and language, or respiratory therapy); mental health care services; care coordination activities; developmental assessments; home care services from nurses and allied health professionals; special equipment; special clothing, supplies and diet; home modification; transportation; special child care and respite services; and educational, vocational, and financial planning to diminish the adverse effect of the illness and its treatment on the child and family's growth, development and future productivity. (Please see Table 1 for a listing of health related and other service needs.) Most families whose children have chronic illness or disability have no need for all these services. However, these services should be available to all families with chronically ill children.

CARE COORDINATION

The coordination of medical care through care coordination results in quality care and efficient, cost-effective use of health care resources and is extremely important. Children with chronic illness disabilities and those who incur catastrophic expenses, whether through a privately-funded or publicly-funded program, should have access to care coordination services.

Families of children with special needs find themselves the victims of uneven service. The nature of human service programs themselves, each with its own planning, reporting and evaluating systems, leads to fragmented service delivery. The complexity of each of these major service delivery systems necessitates cooperation of services across systems (Magrab and Elder, 1980). There are great inefficiencies, opportunities lost, and unnecessary costs incurred when there is not integration of the needs of individuals. Care coordination provides an on-going plan designed for each child specifying medical, nursing, equipment, educational and therapy needs. Care coordination entails continuous monitoring, quality assessment of services, and constant revisions of the plan in response to the child's changing needs and developmental status and the families financial and emotional resources.

Properly constructed care coordination can stop duplication of services, decrease wasted services and avoid unnecessary expenses. The Coordinating Center for Home and Community Care Inc., a case management agency for the Medicaid Model Waiver program in Maryland has documented a dollar saved for every dollar spent by Medicaid during their first 34 months of operation. Servicing 50 medically-fragile children, the total spent for comprehensive services was 3.1 million dollars. Had these children not received community-based services under the guidance of service coordination, the total price would have been 6.2 million dollars.

Care coordination has two components. It includes the coordination of medical care, and the process of assisting families to gain access to, financial support for, and coordination of comprehensive services at the community level. These two components (medical care coordination and community-based service coordination) must both be included in a unified, family-focused, outcome-based plan. The plan must identify all health and related needs, the recommended course of treatment, resources available to pay for care, and methods for filling the gaps in needed services and coverage.

For the medical care coordination component of care coordination, the child's primary care pediatrician is often the best suited by training and experience to be the case manager. He or she can thus ensure the quality and continuity of medical care. Coordination of the wide array of services at the community level, the second component of case management, may be done by the child's primary care pediatrician, social worker, public health nurse, or another professional. In cases in which the pediatrician does not direct community service coordination, it is essential that the case manager actively involve the child's primary care pediatrician. Appropriate reimbursement for the provision of case management services is the responsibility of the public or private insurer paying for the care being managed.

PROBLEMS OF THE CURRENT SYSTEM

Current provision of child health care services is based upon several mechanisms: private and public health insurance, out-of-pocket payments by families, donated professional services and philanthropy. Approximately 86 percent of chronically ill children currently have access to varying degrees public or private health insurance.

These mechanisms, however, as inadequate as they are for most children, are rarely adequate to finance the special health care needs of children with chronic illness, disabilities and those incurring catastrophic expenses. In addition, rarely are these funding sources coordinated. Consequently even when the full spectrum of health-related services is available in a community, services are not used appropriately -- risking less than optimal outcomes, prolonging morbidity and increasing long-term societal costs.

Private insurance fails the child's family because it is often inaccessible, unaffordable or insufficient to finance the preventive and comprehensive care required. Most private insurance comes as an employment benefit. Private health insurance is rarely accessible to unemployed or seasonally-employed parents. For others, individual coverage may be available but family coverage is lacking. Frequently, children are denied coverage because of a "preexisting" condition. Benefit packages typically do not include the full range of services needed by children with long-term health conditions. In addition, the high costs of care required by some children commonly exceeds maximum annual or lifetime limits, and coverage is lost.

Medicaid is the most important public insurance program affecting children. Although there is tremendous variability in program implementation from one state to another, common shortcomings important to the chronically disabled child include: failure of many states to cover an appropriate array of mandatory and optional services; spend-down requirements for medically-needy families which tend to make and keep them financially destitute; restrictions on the type, setting and providers of services which interfere with accessibility and continuity of care; insufficient use of the federal provisions of the Early and Periodic Screening, Diagnosis and Treatment program (EPSDT) allowing supplementation of limited Medicaid benefits; and rigid eligibility criteria which can cause sudden loss of benefits and disruption of treatment continuity when minor and temporary changes occur in family income. Additionally, inadequate and delayed Medicaid reimbursement for services often discourages participation by many of the most appropriate and accessible health care providers.

The Title V Maternal and Child Health Block Grant Program (which includes Services for Children with Special Health Needs, formerly called Crippled Children's Services) is also a public program. Unlike Medicaid, however, these state programs are designed to provide or arrange services for children with specific long-term illnesses. In the past two decades, funding for Title V has not grown in proportion to the population needing services and has been overshadowed by growth in other public programs, especially Medicaid. State agencies have wide latitude in how they implement the program, resulting in great variations in administration, eligibility, and covered services from state to state. (Ireys, Hauck, and Perrin, 1985)

Ultimately, families become the payors of last resort for most underinsured and uninsured care. To obtain needed services without delay and minimize out-of-pocket debt, families in conjunction with a care coordinator must negotiate and coordinate multiple funding sources. Understanding the complexities of these multiple sources (many of which change criteria and policies frequently) remains exceedingly difficult.

A related issue is a problem involving the eligibility of mentally impaired children for disability benefits under the Supplemental Security Income program (SSI). Since SSI eligibility automatically carries with it Medicaid coverage, this is an important issue for those of us concerned with access to health care for low-income children with handicapping conditions.

The Social Security Administration has literally been sitting on a proposed revision of the children's standards of mental impairment for over two years.

Numerous authorities agree that the current standards for determining mental and emotional disorders are so restrictive and unrealistic that tens of thousands of children are improperly denied benefits. In response to pressure from the advocacy community, SSA appointed, in June 1985, a prestigious work group of experts in childhood mental disabilities and SSA senior staff to examine the standards. In April, 1986, after almost a year's study, the work group recommend a new set of standards and procedures to the Associate commissioner for Disability. Recognizing the complexity of a child's development, the work group recommended age-appropriate criteria for five distinct age groups between birth and 18, in 11 categories of mental disorders. In each category, both "clinical signs and symptoms" and functional restrictions would be evaluated.

In the letter accompanying the work group's submission, its chair, Dr. John M. Hamilton, noted that the recommended revisions "are ultimately fairer" than the existing standards "and a reflection of the current state of the art an science where childhood mental impairments are concerned."

Nevertheless, the recommended revision of the listings have been "under review" for over two years in the Social Security Administration, with their publication as a "notice of proposed rulemaking" nowhere in sight.

Hence, new standards should be issued as a proposed rule, so that the medical and disability community can determine whether they are fair and realistic in assessing a child's mental and emotional disorders.

PRINCIPLES

Solutions to the problems of providing and funding comprehensive health care services for children with chronic illness and disability must involve every aspect of today's public and private resource base. Our objective is to assure that needed services exist and that financial barriers to those services are eliminated by creating a community-based, care-coordinated system of quality services in a public/private partnership that protects families from catastrophic medical expense.

Therefore, all health care strategies for children with chronic illness and disabilities must:

1. Assure access to needed health care services for all children without regard to race, religion, national origin, economic status, place of residence, health or functional status;

2. Cover a broad array of services that are comprehensive (including ambulatory, hospital and long-term care equipment and supplies), continuous, cost efficient and to the extent possible, community-based;

3. Provide for a system of case management or care coordination;

4. Assure quality through adherence to established standards of health care;

5. Actively seek the participation of families in the development and implementation of their child's care or treatment plan;

6. Include the child's primary pediatrician as an integral component;

7. Provide reasonable reimbursement to the care provider for the time expended in delivery of all necessary components of the child's care to ensure an adequate supply of providers; and

8. Be affordable to both family and society, and protect family income and assets against catastrophic medical expenses by adopting a catastrophic insurance mechanism.

Each child with a chronic illness or disability who requires health care services over a long period of time should be sufficiently insured to provide for:

o A comprehensive plan of care or treatment specific to the child's and family's needs. The plan should integrate all aspects of care -- including health, social, educational and vocational.

o Care coordination to ensure that the family and child's health needs are met, interagency responsibilities are coordinated, services are delivered in a cost-effective manner, and all available financial resources are equitably utilized.

o Quality assurance and followup. Mechanisms must be available to monitor the care provided, assure efficient use of resources, and provide continuity of care on a long-term basis.

III. PROGRAM RECOMMENDATIONS

The following makes recommendations for the Maternal and Child Health Block Grant and the Medicaid program - the two main child health financing programs under the purview of this committee. We believe, however, any true resolution to the complex issues affecting children's access to health care will involve a public/private sector partnership. As such we have also developed recommendations for private insurors, employer-based plans and state level activities.

A. MATERNAL AND CHILD HEALTH BLOCK GRANT

As you know, the Maternal and Child Health Block Grant (Title V of the Social Security Act) is the only public health service program which is devoted exclusively to meeting the needs of mothers and children. As such the MCH Block is a unique and important program whose efforts and initiatives must be strengthened and reinforced.

The purpose of the MCH Block is to enable each state to assure mothers and children access to quality health services, reduce infant mortality and incidences of preventable diseases and handicapping conditions among children, provide rehabilitation services for blind and disabled children under the age of 18 and provide otherwise unavailable services for children with disabilities and chronic illnesses. As such, the Block has a dual focus -- to serve the primary and preventive care needs of all children and mothers and also to help children with special health care needs. Clearly, these are worthy goals.

The program is up for reauthorization next year. We have begun to work with a number of child advocacy groups to develop recommendations which will strengthen and enhance the role of this program and its ability to meet the needs of the mothers and children it is designed to serve. Indeed, the medical environment has changed dramatically since the enactment of this block, both in areas of medical technology and treatment and financing for an array of needed services. It is important that we examine the design and ability of this program to meet the complex needs of today's children and their families -- needs that involve a range of services from health, education, social services and other areas. The block must be assessed with respect to its responsibility for children and families for preventive, sick and catastrophic care coordination.

Although it is premature to discuss the details of any such proposal, several concepts are clear. First, there is a need to ensure that the needs of mothers and children are carefully assessed and a plan developed to meet those needs. At a minimum we believe these plans should 1) identify the unmet health needs of mothers and children; 2) identify availability of resources for unmet needs; 3) assess children's access to care, including the types of services they are receiving the payment vehicle; 4) set specific and measurable goals for improving services and health outcomes; 5) specify steps to be undertaken to attain these goals; and 6) specify steps to coordinate efforts among providers and relevant federal supported programs, such as the MCH Block, WIC, EPSDT, family planning, PL 99-457 and Medicaid. Second, there is a pressing need to improve the data collection function through the block -- the number of types of women and children who are being served; their diagnostic conditions; who is paying for their care; and an assessment of unmet need. Third, we support strengthening the accountability provisions in the block -- where dollars are being spent and who is receiving services. Fourth, we believe funds should be made available to ensure that families with children with special health care needs have access to care coordination. Finally, we support mechanisms to improve the coordination of this program with all other state child health programs, for example, Title XIX, Title X, the lead agency under PL 99-457, SSI and WIC, to name a few. The fragmentation of child health programs at the state level continues unabated -- leading to further duplication and fragmentation of services.

In addition, we recommend the Secretary of the Department of Health and Human Services be required to report each year to Congress on the state of our children's health, based on state data. This report should assess children's access to care, including children who are receiving care, the types of services they are receiving, who is providing and financing their care -- as well as unmet needs. Each year the Secretary should set specific and measurable goals improving services and outcomes and steps to attain these goals.

We will continue to work with a consortium of child advocacy groups to develop these concepts into specific recommendations for consideration next year.

B. EXPAND AND IMPROVE MEDICAID

While the incremental improvements in allowable Medicaid benefits and eligibility over the past years has helped, the enormous variations and limitations in state coverage have resulted in nonexistent or ineffective programs for many children. The present system, by offering better health care coverage to a child because of geographic location, is inequitable and discriminatory. We recommend the following:

1. Mandate eligibility for all pregnant women and children through age 21 years regardless of family structure, whose family income is less than 100% of the federal poverty level.

2. Permit states to extend eligibility to children through age 21 whose family incomes are between 100-200% of the federal poverty level. Allow states to charge an income-adjusted Medicaid premium of no greater than 10% of that family income greater than 150% of the poverty level.

3. Mandate state extension of Medicaid to children with chronic illnesses in families with incomes between 100-200% of the federal poverty level and those who incur catastrophic expense. These children should be entitled to an enriched package of benefits.

4. Permit optional purchase of Medicaid for families with chronically ill or disabled children whose incomes are greater than 200% of the federal poverty level, where no other source of health insurance exists. The premium charged should be no greater than 10% of family income. Coinsurance obligations, assessed on a sliding scale basis, may be considered.

5. Mandate Medically Needy Programs in all states.

6. Assure that all children with disabilities receive EPSDT services, thus rendering them eligible for enriched services under Title XIX even if these services are not provided for other state Medicaid beneficiaries.

7. Improve reimbursement rates to health care providers to enhance access to care

A word about the last recommendation. As has been made dramatically clear by the current crisis in obstetrical services, reimbursement problems affect women and children's access to care. As the committee examines these problems we encourage you also to review the problems associated with children's access to pediatric care. As you know the Academy's advocacy has always focused on improving eligibility for Medicaid, the benefits package and amount, duration and scope of services. These continue to be our priority concerns. Nevertheless, reimbursement problems continue to pose a barrier to children accessing needed care and should be addressed.

In summary, Mr. Chairman, I would like to quote from the Hastings Center report on the imperiled newborn which includes, "American social policy is simply not meeting the needs of its most vulnerable citizens -- children with disabilities and chronic illnesses and their families. As acute care medical technology and expertise grows, the number of children with disabilities and chronic illnesses and the number of families who will care for them will continue to grow. We believe that the ethical case for according a far greater priority to meeting the basic medical, economic, and social needs of these children and their families is self-evident. Society has a specific moral duty to address the needs of children who cannot realize their full potential in society without the assistance of others."

The Academy and all the other pediatric child advocacy and disability organizations represented by this testimony are eager to work with your Committee to enact many of these reforms and create an improved child health care financing system. We thank you for your continued support and interest in these areas and look forward to our future efforts.

APPENDIX I

Health Related and Other Needed Services

1. Hospital, Inpatient or Residential Care*
   - Acute Hospital Care
   - Physical Rehabilitation Facilities
   - Intermediate Care Facilities
   - Skilled Nursing Care
   - Discharge Planning
2. Outpatient Care
   - Primary Care from Physicians
   - Consultations with Specialists
   - Care at Special Clinics or facilities
   - Developmental Assessments
   - Emergency Care
   - Dental Care
   - Laboratory Procedures
   - Home Care
   - Respite and Child Care Services
   - Genetic Counseling
3. Care or Case Coordination
   - From Physicians for Health Care Coordination
   - From Nonmedical Professionals
4. Allied Health Professional Services
   - Nursing Care
   - Physical Therapy
   - Occupational Therapy
   - Speech Therapy
   - Respiratory or Inhalation Therapy
   - Social Services
   - Psychological Services
   - Vocational Counseling
   - Nutritional Assessment and Counseling
5. Medications, Supplies, Special Diets
6. Special Equipment
7. Special Clothing
8. Special Education
9. Home Modifications in Special Circumstances
10. Specialized Transportation
11. Financial Planning

*Other than Community Residences or other Community Living Arrangements

STATEMENT OF SENATOR JOHN HEINZ
COMMITTEE ON FINANCE
MAY 24, 1988

MR. CHAIRMAN, TODAY THE COMMITTEE WILL FOCUS ON THE BASICS, PRIMARY HEALTH CARE FOR AMERICA'S CHILDREN. THERE ARE FORTY-FIVE MILLION CHILDREN UNDER AGE THIRTEEN IN THE UNITED STATES AND PRIMARY CARE INCLUDING DOCTOR VISITS, IMMUNIZATIONS, VISION AND HEARING CHECKS, AND DENTAL CARE and more ~~MORE~~ CAN MEAN A BRIGHTER FUTURE FOR ALL OF THEM.

APPROPRIATELY, CONGRESS HAS MADE EARLY AND CONTINUOUS PRENATAL CARE ITS STARTING POINT. OVER THE PAST FEW YEARS, WE HAVE MADE PROGRESS IN EXPANDING ACCESS TO HEALTH CARE FOR PREGNANT WOMEN AND INFANTS. NOW, WE WILL LOOK BEYOND ENSURING A BLESSED EVENT TO ANOTHER BUILDING BLOCK, WELL-CHILD CARE.

THE MEDICAID PROGRAM IS THE HEALTH INSURER FOR ELEVEN MILLION CHILDREN. ONE-HALF OF OUR NATION'S POOR CHILDREN UNDER AGE THIRTEEN BENEFIT FROM THIS NATIONAL FEDERAL-STATE PARTNERSHIP. DUE DIRECTLY TO THE WORK OF THIS COMMITTEE, WE CAN EXPECT THAT MEDICAID'S ROLE AS A HEALTH SAFETY-NET FOR POOR CHILDREN TO GROW. THE LATEST COUNT SHOWS THAT FORTY STATES HAVE PLANS TO COVER CHILDREN WITH FAMILY INCOMES BELOW THE POVERTY LINE. YET, ONE-THIRD OF POOR CHILDREN, AND NEARLY TWENTY-PERCENT OF ALL CHILDREN UNDER AGE THIRTEEN ARE UNINSURED.

ONE COMPONENT OF MEDICAID THAT COMMANDS OUR ATTENTION IS THE EARLY, PERIODIC, SCREENING, DIAGNOSIS AND TREATMENT PROGRAM (EPSDT). CONGRESS ENACTED EPSDT IN 1967, BUT IT WAS NOT UNTIL 1985, THAT REGULATIONS WERE FULLY

IMPLEMENTED. EPSDT IS A MANDATORY PROGRAM DESIGNED TO PROVIDE COMPREHENSIVE SCREENING SERVICES TO ALL MEDICAID ELIGIBLE CHILDREN UNDER AGE TWENTY-ONE. YET, OF THE ELEVEN MILLION ELIGIBLE, ONLY THREE MILLION RECEIVED THESE EXPANDED SERVICES WHICH INCLUDE VISION AND DENTAL CARE.

WELL-CHILD CARE IS ALSO PROVIDED AS A MEDICAID SERVICE IN THIRTY-TWO STATES, ADDING TO THE NUMBER OF CHILDREN RECEIVING PREVENTIVE SCREEING. DURING OUR REVIEW OF CHILDREN'S HEALTH PROGRAMS, I HOPE THAT THE COMMITTEE WILL EXAMINE THE BARRIERS WHICH MAY EXIST WITHIN THE MEDICAID SYSTEM, SPECIFICALLY REGARDING THE EPSDT PROGRAM.

THE MATERNAL AND CHILD HEALTH BLOCK GRANT EXCLUSIVELY FUNDS PROGRAMS AND SERVICES TO IMPROVE THE HEALTH OF MOTHERS AND CHILDREN. THIS YEAR, STATES WILL RECEIVE $444 MILLION DOLLARS TO ACHIEVE CRITICAL PREVENTIVE HEALTH GOALS. THIS GRANT PROGRAM FORMS LINKAGES BETWEEN THE WIDE RANGE OF FEDERAL PROGRAMS INCLUDING STATE MEDICAID AGENCIES; MATERNAL AND CHILD HEALTH FUNDED SERVICES; THE SPECIAL SUPPLEMENTAL PROGRAM FOR WOMEN, INFANTS, AND CHILDREN (WIC); AND AGENCIES AT THE LOCAL LEVEL, ENHANCING COORDINATION AND IMPROVING COOPERATION.

I LOOK FORWARD TO REVIEWING TODAY'S TESTIMONY AND WORKING WITH THE COMMITTEE AS WE CONSIDER OPTIONS TO ENSURE A HEALTHY FUTURE FOR ALL.

THANK YOU, MR. CHAIRMAN.

STATEMENT OF SENATOR JOHN HEINZ
COMMITTEE ON FINANCE
MAY 26, 1988

MR. CHAIRMAN, FIRST I WANT TO COMMEND YOU FOR YOUR FORESIGHT IN CALLING THIS SERIES OF HEARING ON CHILDREN'S HEALTH. OVER THE PAST YEAR, WE HAVE HEARD EXPERT TESTIMONY ABOUT THE HEALTH NEEDS OF OUR MOST VULNERABLE YOUNGER AMERICANS. CHILDREN REPRESENT THE FUTURE OF THIS COUNTRY AND THEY NEED CAREFUL CONCERN OF THIS COMMITTEE.

IN A RECENT REPORT, HEALTHY CHILDREN: INVESTING IN THE FUTURE, THE OFFICE OF TECHNOLOGY ASSESSMENT ESTIMATES THAT AS MANY AS 8 MILLION CHILDREN UNDER AGE 13 HAVE NO HEALTH INSURANCE. MOST OF THESE CHILDREN ARE FROM POOR AND NEAR-POOR FAMILIES. UNINSURED CHILDREN LACK APPROPRIATE DOCTOR CARE AND HAVE FIFTY-PERCENT LESS HOSPITAL VISITS THAN INSURED CHILDREN.

THE NEED FOR HEALTH CARE BEGINS BEFORE BIRTH AND EXTENDS THROUGHOUT OUR LIVES. OFTEN, OUR MEDICAL SYSTEM PLACES LITTLE EMPHASIS ON PREVENTIVE CARE. THE EVIDENCE IS CLEAR, PARTICULARLY IN THE CASE OF INFANT MORTALITY, THAT AN OUNCE OF PREVENTION CAN MEAN A TON OF CURE. FAILURE TO DIRECT ATTENTION ON PRENATAL CARE PRODUCES DEVASTATING RESULTS.

NEARLY SEVEN PERCENT OF ALL INFANTS ARE BORN AT LOW BIRTHWEIGHTS EACH YEAR. FOR MORE THAN THIRTY YEARS, EXPERTS HAVE REPORTED THAT LOW BIRTHWEIGHT BABIES ARE AT THREE TIMES THE RISK OF DEVELOPING CEREBRAL PALSY, SEIZURE DISORDERS AND OTHER PERMANENT CONDITIONS. FURTHER, LEARNING PROBLEMS, NOT IMMEDIATELY DETECTED IN THE DOCTOR'S OFFICE, LIMIT THESE CHILDREN AND THEIR EDUCATIONAL SUCCESS.

SOMETIMES, DESPITE EVERY EFFORT, CHILDREN ARE BORN WITH SPECIAL NEEDS. FORTUNATELY, THE NUMBERS ARE SMALL, ABOUT 3 MILLION OF THE NATION'S 60 MILLION CHILDREN UNDER AGE 18 HAVE SERIOUS MEDICAL CONDITIONS WHICH LIMIT THEIR DAILY LIVES. FOR THESE CHILDREN AND THEIR FAMILIES, HOWEVER, THIS STATISTIC HOLDS NO COMFORT.

A CHILD'S ILLNESS CAN BE DOUBLY CATASTROPHIC WHEN THE MEDICAL COSTS MOUNT UNCONTROLLABLY. EACH YEAR, 19,000 CHILDREN NEED INTENSIVE MEDICAL CARE COSTING OVER $50,000. ONE-HALF OF THESE CHILDREN HAVEN'T EVEN HAD THEIR FIRST BIRTHDAY. INDEED, BLESSED EVENTS AND THE BOTTOM LINE, A REPORT BY THE ALAN GUTTMACHER INSTITUTE, REVEALED THAT ONE-THIRD OF UNCOMPENSATED HOSPITAL CARE IS FROM THE MATERNITY WARD AND THE NEONATAL INTENSIVE CARE UNIT. THIS $7.4 BILLION DOLLARS PER YEAR IS THE SINGLE LARGEST SOURCE OF UNPAID HOSPITAL DEBT.

THERE IS MUCH LEFT TO DO BEFORE WE CAN DECLARE VICTORY IN OUR FIGHT TO PROVIDE EVERYONE THE OPPORTUNITY FOR A HEALTHY START. FOR THIS REASON, I WELCOME THE INSIGHT'S OF TODAY'S WITNESSES.

THANK YOU, MR. CHAIRMAN

TESTIMONY TO SENATE FINANCE COMMITTEE

May 26, 1988

The Association of Maternal and Child Health Programs is heartened by these Finance Committee Hearings on the health of mothers and children. We are pleased to share here our recent experience in state maternal and child health programs. Our perspective will be drawn from MCH experience that extends back before the Social Security Act, but we will emphasize unmet needs and child health issues that require national attention today. We are here to call for a renewed national commitment to assure better family health by the twenty-first century. We shall propose several concrete steps to assure better health for America's families. Our recommendations will fall into three headings: Better Coverage for Care, Stronger Health Leadership and Accountability, and Stronger Public Health Programs.

Maternal and Child Health agencies exist to preserve, protect, and promote the health of children. We believe that every American child should be born well into a family and community that will actively support her optimal health and development. Children with significant illness or disabilities should be assisted by full, coordinated, family empowering services to meet their special health needs. We also believe there is a public health responsibility to study and monitor the health and development of all children, to plan for an effective system of health and developmental services, to assure that every child and family receives care when it's needed, and to account for the quality and results of our health care investments. We believe good maternal and child health is the foundation for growth and strength of individuals, families, communities, and the nation.

Maternal and Child Health Leadership

To assure the health of children in America, and the ability of America's families to support health and developmental care, there must be a public responsibility to assess the health status of all mothers and children, to define unmet needs and problems, and to develop plans to address them. Title V programs are unique in their focus on child health, and their responsibility to study and plan for the future. This commitment to data and planning is the foundation of MCH leadership. Although leadership and advocacy are not mandated, they are a Title V tradition since the earliest days of the Children's Bureau..

The particular Title V mandate to serve low income families, and those with children who have special health care needs, has been an enormous challenge in recent years of rising costs and reduced coverage. Title V agencies have struggled valiantly to provide primary and specialty clinical services in an attempt to fill large gaps in America's child health care coverage. Unfortunately, the needs are far beyond public health budgets, and the attempt has sometimes weakened data, planning, and other fundamental public health responsibilities. Nonetheless, since 1981, under limited and unstable Block Grant funding, we have led the expansion of prenatal Medicaid services and the development of home care for technology dependent children in most states.

Assuring Effective Systems of Care for Families with Children

Title V also has a responsibility to assure standards for the quality and content of maternal and child health care and to evaluate care and outcomes. MCH agencies are uniquely placed to see if services are available, accessible, affordable, comprehensive, coordinated, and responsive to family health needs. The specific means by which each state assures care for mothers, children, and families varies, due to differences in needs, state agency structures, and resources. However, the role of MCH programs is critical in every state:

A. Title V programs provide information, outreach, training, and assistance to families and professionals on prevention of health problems, support of children with special health care needs, and effective use of existing services. For example, Illinois is using its earmarked funds to develop a resource/rights workbook for parents, to train case managers and parents to do home assessments for medically fragile children, to produce training materials for families and professionals who plan home and community care, and to develop public/private collaborative outreach strategies.

B. Title V programs develop and monitor standards of care for public and private providers and payors. To address concerns about the content and quality of maternity care for low income patients, a committee of Title V and Medicaid directors has recently distributed a set of model guidelines for pre and perinatal care that can be used nationwide. These guidelines were derived from standards of care developed in nineteen state MCH programs.

C. Title V programs develop systems of family centered health care financed by a variety of payors, including Medicaid and private insurance. Many Title V programs have designed systems of home care for technology dependent children. These programs of care coordination work with Medicaid waiver and private insurance initiatives to insure medically safe home environments at demonstrated cost savings.

D. Title V programs develop and test new program models to meet emerging health problems. The MCH Block Grant set-aside funds support Special Projects of Regional and National Significance (SPRANS) which have assisted states to address new challenges. These grants have been important catalysts to the development of regionalized perinatal care, new case management models, improved services for adolescents, health services in day care, and, most recently, pediatric AIDS demonstration projects. For example, a SPRANS grant to the Hawaii MCH program has establish a statewide multiagency adolescent health network which integrates resources and care at the state and community levels.

E. Title V programs coordinate the planning, delivery, and financing of health and related services. One outcome of a Michigan Blue Ribbon Task Force on Infant Mortality was the designation of prenatal care as a basic health service in the state. The Health Department established the Prenatal/PostPartum Care Program to assure access for low income uninsured women, and to promote high quality comprehensive care. In 1986, program participants had an infant mortality rate of 7.6, compared to 11.4 for the state. Many other states, including Rhode Island, have convened special task forces or committees, whose work has resulted in major improvements in maternity care.

F. Title V programs provide or arrange case management for families, to assist them in integrating health, welfare, social service, and educational programs for their special needs children. Since the 1970's, the Title V SSI Disabled Children's Programs have led the way in formalizing the practice of care coordination. Through this model of comprehensive community-based services, Title V programs have developed extensive expertise, which is now being used for other groups of children, including those eligible for early intervention programs under PL 99-457, and those with catastrophic health costs served by Medicaid. For example, the Texas SSI DCP has served three year old Lee, a Hispanic child born with Down Syndrome, stomach and heart defects. His parents do not speak English. His case manager helped them work with the service system and coordinate care at three separate hospitals, negotiate payment terms and reduced cost services. Lee's condition is now stabilized, and the strain on his parents' marriage is diminished.

G. Title V programs assess the adequacy of health care systems. Our survey of states' programs includes many statewide assessments of children's service needs, using vital statistics, census data, Medicaid and hospital discharge reports, and specially designed consumer and provider surveys. For example in nineteen states, the Title V and Title XIX programs have worked to link their data and give a better picture of patient characteristics, services, health outcomes, and costs in both programs.

H. Title V programs provide direct care services where they are unavailable through other public or private providers. In many states, Title V programs remain a major resource, especially in medically underserved areas. For example, in 1987 Alabama's Title V program supported maternity care for over 20,000 women. One-third of Alabama's counties still lack organized obstetrical care, and so, working with a coalition of forty-four professional, provider, civic, and religious groups, the Alabama Health Department has developed proposals to improve both public health and Medicaid programs. Medicaid eligibility will now be increased to the poverty level, and every county health department will be required to offer prenatal and child health care. Thus, public health leadership has addressed both coverage and provider problems throughout the state.

In 1988, we are emerging from a period of cuts in the human services that mean most to children and their parents. Our surveys of state MCH programs show great unmet needs. The data also suggest a substantial change in roles and budgets of our child health investments. MCH programs are most effective when limited federal dollars are used to develop systems, catalyze change, and leverage innovative health care models. In fact, the widespread success of recent Medicaid extensions and waiver programs could only have occurred with public health leadership. In state after state, planning, training, standard setting, and, often, direct management of these programs has depended upon Title V agencies. In this work, we recognize that coverage does not assure care or quality. As state MCH directors, we are committed to bring good care to all children in their communities. We hope the Committee will recognize that the nation needs a similar societal commitment and vigorous public health leadership in order to make major, lasting changes. To that end, the AMCHP recommends the following:

America Needs Universal Health Care Coverage that Promotes Healthy Children.

- Our long-term goal must be simple, universal coverage that assures a common standard of health care for all citizens, including preventive, developmental, care coordination, and catastrophic health benefits. Coverage should be direct, easily understood, and welcoming. Such coverage should be extended to women and children first.

- In the near term, we must extend and improve existing financing mechanisms. We support current proposals to strengthen employment- based family coverage. We strongly endorse the Bradley-Chafee-Waxman Medicaid extensions now before the Congress.

- To assure that better coverage leads to good care, Title V should include explicit responsibility to establish standards for both coverage and care, and to evaluate outcomes in relationship to coverage. This mandate should also be reflected in other relevant federal legislation.

America Needs Strong Public Health Leadership for Healthy Children

- America's Health Objectives for the Year 2000 should be ambitious and comprehensive in their treatment of child and family health. America should be in the highest ranks of child health by the next century. We recommend convening a 1990 White House Conference on Child and Family Health, to be sure our national agenda will get us to those objectives.
- The Bureau of Maternal and Child Health in the Public Health Service should be charged, staffed, and funded to renew the nation's data base on children's health, to support training and technical assistance for Title V programs, and to serve as agent for national maternal and child health planning and accountability.
- We support a mandated national system of state MCH plans and reports, to include assessment of unmet needs, services, and outcomes. Reports should be keyed to the Health Objectives for the Year 2000. Prompt common reporting to the Bureau should be aggregated into an annual national report on the health of children and parents. The report should include state-specific data, and should highlight major unmet needs in specific populations. Title V resources will be needed to reinstitute MUCH planning and accountability.

America Needs Strong State and Local Maternal and Child Health Programs

- Title V is up for reauthorization in the coming year. We should take this opportunity to strengthen both the public health mandate and our information base for each major maternal and child health population noted above. The charge to assess needs, plan, educate, coordinate, set standards, and evaluate should be applied to all major maternal and child health programs. A substantial increase in the authorization level will be needed to meet these MCH needs and Title V responsibilities.

- The Title V mandate should still allow state and local programs to deliver direct services where needed and fill gaps in our fragmented health care system, but we should encourage uniform, universal approaches to child health..

- Title V programs should be clearly designated as lead agencies for care coordination for children with catastrophic health care costs, as proposed in S1537, the Care Management and Catastrophic Health Care for Children Act of 1987. State agencies need a clear mandate and new resources to provide or arrange appropriate family centered, community based care management services for all children with major special health care needs, without diagnostic or other restrictions.

- Title V should strengthen its mandate and resources to assure preventive and community services not commonly covered or offered by clinical providers. This responsibility should focus on low income, and high risk populations and should coordinate with Medicaid. Community based outreach and preventive services should first be developed to assure risk-responsive maternity care for all women in every state.

- Conforming legislative and/or regulatory changes should be made in related programs, especially Medicaid and the Education for the Handicapped Act, to reinforce the mandate for cooperation, standards, and accountability in joint programs.

All of these challenges will require a new American commitment--a commitment of resources, of leadership, and most of all, a societal pledge to make children's health our highest priority for the next decade. State maternal and child health leaders are eager to join the Committee and many other allies to bring us the healthiest children in the world by the year 2000.

WHH:VCD

EMERY A. JOHNSON, MD, MPH

I am pleased to have the opportunity to appear before your committee to present my views on the health of American Indian and Alaska Native (AI/AN) people and on the Federal government's efforts to elevate their health status to the highest possible level as mandated by the Indian Health Care Improvement Act (PL 94-437). Although the Federal government's principal agency with responsibility in this area, the Indian Health Service (IHS) of the Department of Health and Human Services (DHHS), is not within the specific jurisdiction of this committee, the limited resources available to IHS make many of the programs under your authority vital to the health of this population.

My concern for the health of AI/AN people is based on over three decades of experience, of which more than 26 were as a member of the IHS -- reservation physician, Indian medical center director, area and headquarters official, including 12 years as the Director of IHS. Since my retirement in 1981, I have continued to be actively involved with Indian health as a consultant to national and regional Indian organizations, Indian tribal governments and other organizations with interests in Indian health. My views are based on my past and present experience with the Indian health program and with tribal leaders, health staff (both IHS and tribal) and other experts in the field of public health and health services delivery.

American Indian and Alaska Native people have a unique relationship to the government of the United States, a relationship anchored in the Constitution of the United States, implemented through treaties and public laws and repeatedly affirmed by the Supreme Court. In spite of the shameful record of the Federal government in honoring its treaties with the Indian nations, the Federal courts have supported the validity of the treaties. From Chief Justice John Marshall who, in support of the Cherokee Nation, stated in 1831 that "all of these Acts ---- manifestly consider the Indian nations as distinct political communities, having territorial boundries, within which their authority is exclusive, which is not only acknowledged , but guaranteed by the United States" to recent decisions, such as that of Santa Clara Pueblo v. Martinez (1978) which affirmed the right of Indian tribal governments to determine their own membership and

Mancari v. Morton (1974) which again confirmed the unique relationship of Indian tribes by stating that special programs for Indians were not based on race but on a unique legal, political relationship, the Supreme court has established firmly in the law not only this relationship but the responsibility of the Federal government to honor its treaties with Indian tribes. It should also be recognized that individual AI/AN people are citizens of the United States and are entitled to participate in all Federal and state programs on the same basis as any other citizen.

In 1970, President Nixon submitted an Indian policy statement to the Congress which was to have a significant impact on Federal-Indian relations. The President noted that Federal-Indian relations were based on the United States Constitution and on treaties between the US Government and the governments of Indian tribes - a government-to-government relationship. He stated that the United States honored its treaties and that this relationship was to be maintained. He further advanced the concept of tribal "self-determination", proposing that Federal programs provided to tribes be "taken over" and managed by the tribal governments. The President stated "The time has come to break decisively with the past and to create the conditions for a new era in which the Indian future is determined by Indian acts and Indian decisions".

Naturally suspicious of any new Federal proposal, most Indians initially opposed the "take over" proposal. However, after several years of study and consideration, the Congress, with the support of most Indian tribes, passed the Indian Self-determination and Educational Assistance Act (PL93-638) in 1975. That Act affirmed the government-to-government relationship in law and provided that any Indian tribal government could, upon request, take over the operation of any function, except trust functions, provided by the Bureau of Indian Affairs or the Indian Health Service. Since that time, there has been a relatively stable Federal-Indian relationship, with important advances in the scope and quality of tribal governments. A number of tribes exercise full authority over governmental functions as well as over health, social services and education functions. Much remains to be done but the basis for a sound and effective Federal-Indian governmental partnership is in place.

While the relationship between the government of the United States and Indian tribal governments is complex, I find it is easier to explain it in business terms. Indian treaties were a contract between the Federal government and the tribal governments. As in any contract, valuable considerations were exchanged: the Indian tribes gave up their land in return for payments and/or services from the United States government. Many treaties identified health services as part of the Federal government's payment for Indian land. In effect, the tribal leaders paid in advance for health services for their people, paying the premium in the form of the land. Therefore, members of Indian tribes have a prepaid health program and the Federal government has the obligation to continue its payment (including provision of health services to Indians) for Indian lands.

For a hundred years, this Federal responsibility was carried out by the Bureau of Indian Affairs in the Department of the Interior. However, serious concerns about the sorry state of Indian health led to Public Law 83-568, enacted in 1954, which provided for the transfer of all functions of the Secretary of the Interior relating to the conservation of the health of Indians to the Surgeon General of the Public Health Service (PHS). The transfer took place on July 1, 1955 when the principal Federal responsibility for Indian health came under the jurisdiction of the newly created Indian Health Service of the PHS.

Recognizing the magnitude of the problems to be faced and the need for solid information on the status of Indian health, the Committee on Appropriations of the House of Representatives, 84th Congress, directed PHS to make a comprehensive survey of Indian health. The committee report stated "Health services for Indians have been provided by the Federal government for over a hundred years, but in spite of this fact the American Indian is still the victim of an appalling amount of sickness. The health facilities are either non-existent in some areas, or for the most part, obsolescent and in need of repair; personnel housing is lacking or inadequate; and workloads have been such as to test the patience and endurance of professional staff. This all points to a gross lack of resources equal to the present load of sickness and accumulated neglect. Difficult and severe as the problem may be, it can and must be solved, but it cannot be done with timidity. The need and the measures necessary to meet that need must be fully ascertained. The committee is, therefore of the opinion that a careful comprehensive evaluation of the Indian health problem is in order, so as to determine: What is required to bring Indian health to an acceptable level? How long will it take? What is the best estimate of costs?"

The Public Health Service established a survey team, including experts from academic health centers and state health authorities as well as from PHS and, over the next year, did an extensive survey of Indian health including in-depth studies of nine reservations. The results of this study were transmitted to the Congress in February, 1957 and were published as "Health Services for American Indians" (PHS Publication 531). The conclusions of the study were summarized in the following four points: "1. A substantial Federal Indian health program will be required until gross environmental deficiencies among Indians have been corrected; proposed changes are generally acceptable to the Indian community; serious deficiencies of community health and welfare services are well on the way to being overcome; and there is assurance that adequate and sufficient services will be furnished to Indians by non-Federal agencies. In some areas, many years will be required for these developments. 2. All plans for increased utilization of community health resources should be developed in cooperation with the Indians and the community, and will need to be on a reservation-by-reservation basis. 3. Federal Indian health program operations should be planned in light of the adequacy of community resources, and the services available to Indians under State and local programs. 4. Efforts should be made to increase State and local community recognition of obligations and responsibilities to Indian residents on a nondiscriminatory basis."

At the time of the transfer in 1955, it was stated that "Indians of the United States today have health problems resembling in many respects those of the general population of the nation a generation ago. Diseases that are largely controlled among the general population still cause widespread illness and deaths among Indians". This was attributed to inadequate health services, especially preventive health services, along with substandard and overcrowded housing and lack of adequate sanitary facilities.

Health, particularly in its modern concept of optimum physical, mental and social well being, is not easily quantitated. Historically and to this date, health programs have had to use measures of illness and utilization of health services along with mortality and longevity statistics as surrogate measures of health. IHS has followed that pattern from its inception in 1955. Mortality and morbidity statistics were collected in accordance with the then existing procedures by the National Center for Health Statistics (NCHS) and have been modified periodically as NCHS procedures changed. There are nearly three decades of essentially consistent statistical data on the health of AI/AN as well as comparisons to the general United States population.

In general, there has been a shift in Indian mortality away from deaths due to infectious diseases toward chronic diseases and toward greater comparability with the general US population. However, there has also been an increase in Indian mortality due to diseases resulting from human behavior--accidents, chronic liver disease, homicide and suicide--that is not as pronounced in the non-Indian. Comparison of health statistics over the three decades since the transfer shows that infant and maternal mortality rates and death rates from gastroenteritis are now at or below those of the general US population. Life expectancy of Indians has dramatically improved. In 1950, an Indian infant had a life expectancy of 60 years compared to 71.1 in 1980, an increase of 11.1 years. For the same period, life expectancy for the US All Races population increased from 68.2 years to 73.7, an increase of only 5.5 years.

As striking as these improvements in the health status of AI/AN have been, this population still carries an excessive burden of illness. For example, the rates noted above are for the total population served by IHS. Rates for some Indian communities are much higher. In the Aberdeen Area, which includes the states of North and South Dakota, Nebraska and Iowa, the infant mortality rate is 19.3 compared to the AI/AN rate of 9.8 and the US All Races rate of 10.8. Excessive rates of diabetes are found in many Indian communities, with the

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incidence of diabetes in some Southwest Indian communities the highest ever recorded in the world. Excessive mortality from injuries, alcohol abuse, homicide and suicide are also found, particularly in the young adult, although these rates seem to be falling. Lung cancer, formerly a rare occurence in many tribes, is now becoming more commmon, especially in the Northern Plains where cigarette smoking is more prevelent.

Questions have been raised as to the reliability of these data. While the mortality data is reported by the NCHS based on state vital statistics reports, it is probable that race is miscoded on some death certificates. The Indian population, although it is based on Bureau of the Census data modified by usually accepted methods of projecting intercensal changes, is also suspect. It may reflect an undercounting, as is generally thought to be true of minority populations, or it may be overcounted by the inclusion of "Indians" originating outside of the US. Nevertheless, the consistent collection of these data by sources outside of IHS and the magnitude of the changes leaves no doubt that there has been a significant improvement in the health status of AI/AN even though the absolute magnitude of the change may be questioned.

That these improvements in health status have occured in spite of the continued Indian socioeconomic and cultural burdens such as poverty, isolation, educational deprivation and poor housing is all the more remarkable when it is realized that the IHS has been, for all of its more that three decades of service, RATIONING medical care. Every authoritative study of IHS that I have seen agrees that the funding provided to IHS is inadequate to meet the health services needs of AI/AN people. For example, the Office of Technology Assessment study, "Indian Health Care" in 1986 noted this "rationing" of health care and the DHHS Health Care Financing Administration has reported that per capita medical expenditures for Indians has declined by 25% from 1980 to 1987 and that the disparity with similar expenditures for the US general population has doubled during these years.

Recognizing that the rationing of medical care is a fact of life that is unlikely to change in the forseeable future, IHS over the years has developed a "system" of community-oriented primary care that attempts to be accessible to each Indian individual/family/community, provides varied levels of health services competence (e.g.Alaska Native Community Health Aids, Community Health Representatives, public health nurses, sanitarians, physicians) depending upon the size of the population, its geographical location (e.g. isolation) and the health facilities available (e.g. hospital, health centers, etc.), has the responsibility to move the patient to the level of competence required once the patient has accessed the system, is organized to provide for all levels of acute and chronic health care, preventive services and environmental health services as well as staffing ranging from paraprofessionals to highly trained medical specialists, carries out performance and quality evaluations from baseline statistics to continuous collection of disease mortality/morbidity, workload and population statistics on AI/AN and promotes community participation -- Indian involvement in planning, evaluation and operations ranging from health committees involved in information exchange to health delivery systems entirely managed by Indian tribes or Indian organizations. During the past ten years, the movement has been increasingly toward Indian management of the health system.

I have briefly described the unique government-to-government relationship of the Indian tribal governments to the US government, the concept of a prepaid health care plan (in which the Indian nations relinquished their lands to the United States in return for certain payment, in this case, health care to be provided by the Federal government), the concurrent citizenship right of each AI/AN person to fully participate in all Federal and state health programs on the same basis as any other citizen, the remarkable improvements in the status of AI/AN health in spite of a health system, the IHS, that has been rationing medical care since its founding in 1955. The process by which this success has been achieved, an organized health delivery system partnership between the Indian tribal governments and, thru the IHS, the government of the US has been outlined.

It is my view, based on the discussion above, that the present Federal Indian policy is sound, that substantial progress toward meeting the Federal goal of elevating the health status of AI/AN people to the highest level has been made, (although serious burdens of illness still remain) and the continually expanding health partnership between the Indian tribal governments and the government of the United States provides, despite its deficiencies, a viable model for future progress. I respectfully recommend to this committee that you:

1) continue to support the present Federal Indian policy and the appropriations necessary to maintain its viability
2) support the well-conceived and necessary improvements to this policy as proposed in S.129 (The Indian Health Care Amendments) and S.1703 (The Indian Self-determination and Education Assistance Amendments) now being considered in the Senate Select Committee on Indian Affairs
3) routinely consider the unique government-to-government relationship between Indian tribal governments and the United States and make appropriate provision for full tribal government participation in all legislation coming before this committee
4) explore with the Indian tribal governments and the IHS their experience with the rationing of medical care to determine the extent to which this may be helpful in the face of the continuing stress of escalating health care costs of the American people on the Federal budget.

I would be pleased to answer any questions you may have for me.

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BEFORE THE

SENATE COMMITTEE ON FINANCE

CHILDREN'S HEALTH CARE ISSUES

MAY 24, 1988

Presented by
James G. Jones, M.D.
President-Elect

Mr. Chairman, I am James, G. Jones,, M.D., currently President-Elect of the American Academy of Family Physicians. The Academy is the medical specialty society which represents over 60,000 family physicians, residents and medical students. It is my pleasure to appear before you today to discuss the issue of health care for children. I hope that my testimony will help your efforts here in Congress to ensure access to health care for this vulnerable segment of our population -- children.

Family physicians provide ambulatory-based, cost-effective, preventive-oriented care to a broad population of this country. A significant percentage of the pediatric age population is cared for by family physicians. Using data from the National Ambulatory Care Survey (NAMCS), the AAFP estimates that 20 to 25 percent of pediatric care in this country is provided by family physicians. In addition, obstetrics is an integral part of family practice. Family physicians are well aware that quality health care provided during pregnancy and in early childhood influences a child's health throughout life.

Good prenatal care is one of the most important factors in a child's development. Timely access to preventive, diagnostic and therapeutic prenatal services decreases the likelihood of low birthweight and improves the health of the mother. The Office of Technology Assessment estimates that for every low birthweight birth averted by earlier or more frequent prenatal care, the U.S. health care system saves between $14,000 and $30,000 in newborn hospitalization, re-hospitalization in the first year of life, and long-term health care costs associated with low birthweight.[1] Preventive care during pregnancy increases the likelihood of a healthy baby and is cost-effective. Lack of such care, however, is one of the most serious problems facing the poor, resulting in inordinately high rates of infant mortality and low birthweight.

Prompt medical attention for infants and children also is important. Well baby and well child checkups often can detect health problems early in life. With prompt medical intervention many problems causing death or disability may be averted. Immunizations and health education are also a vital part of medical care for infants and children. Family doctors recognize the devastating impact that lack of accessibility to health care services can have on children and their families.

Improving access to health for all Americans is a major goal of the Academy. Promoting and maintaining the health care of children in particular requires a national effort to strengthen public health programs. Therefore, we are pleased with the recent establishment of a National Commission on Children, long advocated by Chairman Bentsen, and look forward to the recommendations of the Commission.

While improvements have been made in access to health care services for mothers and children in poverty, financial barriers remain a problem for many. Lack of adequate financial resources to purchase basic health care and health insurance is a major impediment to adequate health care for many who, although poor, do not meet Medicaid eligibility criteria. As noted by the National Commission to Prevent Infant Mortality, "Because states set their own Medicaid eligibility levels, eligibility varies tremendously among states, from about 16% to 100% of federal poverty ($9,300 for a family of three in 1987)."[2] The report further notes that six million children in families with incomes below the federal poverty level are without Medicaid coverage. Wide variations in state eligibility and benefit rules cause gaps in access to basic health care services, despite the efforts of Congress over the past several years to expand Medicaid coverage of prenatal, infant and child health care.

Another financial barrier to adequate health care for the Medicaid population is the inadequate reimbursement for prenatal and child health care under this program. For example, according to the National Commission to Prevent Infant Mortality, Medicaid reimbursement for maternity care is far below the prevailing rates for these services in some areas, and the increasing cost of liability insurance adds to an already difficult situation.[3] This can result in some physicians choosing not to serve Medicaid patients.

Legislation to reduce barriers to health care under Medicaid for low income pregnant women and infants recently has been introduced by Senator Bradley and a number of members of the Subcommittee. The bill, currently under review by the Academy, improves the Medicaid eligibility process for pregnant women and infants and also offers equitable reimbursement for obstetrical services. We are encouraged by the approach in this legislation to reduce health care access problems for this population by expanding eligibility and encouraging participation by physicians.

Even among working families above the poverty level access to health care can be a problem for those who lack insurance, have insufficient coverage, or have children with special health care needs. Families with chronically ill or disabled children incur major medical expenses on a long term basis. Benefits from private health insurance coverage often are inadequate, resulting in catastrophic out of pocket expenses. Medicaid is a financing source for poor children but many families do not meet the eligibility test. Legislation has been introduced to allow states the option of extending Medicaid coverage to individual children with these special health care needs. The Academy supports efforts to increase access to health care by chronically ill or disabled children through private insurance and Medicaid coverage. Far too often these children do not receive adequate health care causing the condition to become even more severe.

In conclusion, the American Academy of Family Physicians supports initiatives to improve access to health care through increased coverage of maternal and child health care services in employer provided health insurance plans and in the publicly funded programs. We support reform of Medicaid to achieve more consistent eligibility standards and equitable coverage, so that benefits can be extended to a larger share of this population. Such measures can enhance child health, improve the quality of life and ultimately reduce costs to the health care system.

Mr. Chairman, I have appreciated the opportunity to appear before you today and would be pleased to answer any questions at this time.

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[1] Healthy Children: Investing in the Future. Office of Technology Assessment. February 1988, p. 9.

[2] Infant Mortality: Care For Our Children. National Commission to Prevent Infant Mortality, January, 1988, p. 10.

[3] Malpractice and Liability: An Obstetrical Crisis. National Commission to Prevent Infant Mortality. January 1988, p. 10.

TESTIMONY OF
BARBARA D. MATULA

My name is Barbara Matula. I am the Director of the North Carolina Division of Medical Assistance, past chair of the State Medicaid Directors' Association, current chair of the American Public Welfare Association Task Force on Access to Health Care, and a member of the National Commission to Prevent Infant Mortality. I am here today to speak as a representative of the State Medicaid Directors' Association about the need for improved primary and preventive health care for infants, children, and adolescents.

THE GOALS OF PRIMARY CARE:

The goal of any system of primary health care for children should be to improve overall access to comprehensive health care services, particularly for the disadvantaged. Improvement in access should, in turn, promote reductions in infant mortality, childhood disease and childhood disabilities. These reductions can be facilitated through provision of early, comprehensive and continuous care.

Comprehensive well-child care necessarily includes access to: growth and development assessment; screening, diagnosis and treatment; adequate nutrition; immunizations; automobile safety and accident prevention. Lack of early, comprehensive and continuous care can, and often does, result in undesirable, but preventable, health outcomes.

Access to care can only be improved if the barriers which exist are removed.

OPPORTUNITIES FOR IMPROVEMENT IN ACCESS TO CARE:

There are several broad areas which currently pose access difficulties for poor children and their families. These are areas where there is an opportunity to remedy the situation.

Fragmentation:

There are a myriad of individual programs at the federal, state and local levels that provide access to, and actual services for, infants, children and adolescents. What is remarkable here is that the very existence of all these programs indicates the lack of any unified, comprehensive system by which to assure comprehensive and continuous care that begins early in life for our children. The fragmentation and lack of coordination often results in low participation rates among both providers of care and potential beneficiaries. Lack of coordination means that there is duplication of effort at the same time that many children fall through the safety net that is the Medicaid program and the Public Health system. Although some states and localities have begun to address this issue, considerable effort will be needed to rectify the current situation.

Eligibility:

Aside from the issue of fragmented services and delivery systems, there is the issue of eligibility. Much has been done in recent years to extend health care access to greater numbers of pregnant women, infants, and very young children. Specifically, the enabling legislation that permits states to raise Medicaid eligibility standards to 100 percent of federal poverty levels for infants and pregnant women was a significant and positive action. Thirty four states currently employ this option. Further legislation now allows states to cover children and pregnant women up to 185 of the federal poverty level. Three states now cover children and pregnant women up to this newest level, while another eight are seriously considering this option. As we can see, the separation of cash assistance eligibility and Medicaid eligibility was welcomed by a majority of states and has undoubtedly improved financial access to health care for infants and very young children. The option to pursue presumptive eligibility for pregnant women has also helped facilitate access to necessary care in many states.

Although many states have raised eligibility levels and others have instituted presumptive eligibility for pregnant women, there is still more that can be done.

There are now mechanisms is place in many states to expand eligibility for infants and young children. However, needy adolescents are still subject to the more restrictive Medicaid eligibility criteria which is tied to AFDC eligibility. This means that many needy youth do not have access to needed acute or preventive care services.

Within presumptive eligibility, there is a need for greater flexibility and simplification of the requirements. Current regulations require periodic reapplication and additional applicant visits within limited time frames. Additionally, only services that are judged to be pregnancy related may be covered under the program. This is a very difficult judgement to make and may result in inadequate prenatal care.

Overall, Medicaid program eligibility is geared toward ensuring that only the most destitute and stalwart gain access. The procedures and paperwork are confusing to applicants while general eligibility requirements focus on ensuring that no one with personal resources in included. Eligibility is not continuous, which discourages beneficiaries from reapplication. Eligibility determination is further encumbered because it typically is not available at the location of care and requires separate trips to the welfare office in many instances.

EPSDT:

Within the Medicaid program, the Early and Periodic, Screening Diagnosis and Treatment (EPSDT) program offers needed services to infants, children and adolescents. It presents a good model for case management, continuity of care, and comprehensive, preventive services. EPSDT suffers, however, from the same eligibility constraints as the overall Medicaid program while it has some unique barriers to access as well.

The EPSDT program has not achieved its full potential because there is no provision for automatic enrollment into the program. As currently required, there must be active consent from the parent or guardian before a child can receive services. Although states comply with the program notification, or informing, guidelines, enrollment remains low due to confusion on the part of the beneficiary about what services are provided and their significance to the health of their children.

The informing process occurs at the end of the lengthy eligibility interview when the eligibility worker may not provide a thorough explanation of the services offered and the parent may not fully comprehend the program. Automatic enrollment, except in cases of active refusal, would be much more effective.

Continuity of Care/Provider Participation:

Eligibility issues have a significant, and adverse, effect on continuity of care for children. Beneficiaries must periodically reapply for eligibility which means that there can be gaps in access to care. Additionally, Medicaid is an on/off program, where even minimal increases in wages or resources can result in total loss of coverage. At best, this makes it difficult for a provider to plan a program of care. At worst, it deters provider participation because there is a good possibility that they will be faced with the difficult decision of terminating care or providing care for free if the patient loses coverage.

Another aspect of the provider participation issue is the amount of paperwork and administrative time required of the participating physician in order to receive payment. These requirements, coupled with low reimbursement rates, makes participation unattractive to physicians who can spend less administrative time and be assured payment from private-pay patients. The issue of who should be responsible for collecting on third party payments is complicated, but it must be reviewed if we hope to improve provider participation.

Preventive Care:

Outside of the EPSDT program, for which all poor children and adolescents are not currently eligible, there is little orientation toward preventive care within the Medicaid program. This has been an historical problem for society as a whole which goes beyond the Medicaid program that has only recently begun to be addressed. Outside the parameters of the Medicaid program, we should more thoroughly address the issues of accident and automobile safety. These are the two most common causes of death of children in our society.

Comprehensive preventive care within Medicaid requires identifying and correcting nutritional deficiencies, and development of risk assessment measurements that can identify high risk children eligible for case management services. This will require greater coordination among services and agencies, as I mentioned earlier.

Education and Outreach:

Among the economically disadvantaged, indeed among the population as a whole, there is not a great deal of awareness about the benefits of prenatal and other preventive care. It is not the manner in which society has been accustomed to think. This is most true among the populations who have had the least access to care. Lack of access to even acute care has made preventive care out of the question.

What we need, therefore, on a national level, is an outreach or marketing strategy that will promote wellness, preventive care and safety for our children. This type of public education is vital to the success of all our other efforts. Without this key effort, our hopes to improve the health of the nation's children will be compromised.

FRAMEWORK FOR ACTION:

There are several significant areas where improvement is needed in order to best assure adequate health care for children. What follows are several recommendations that can provide a framework for action.

1) **Promote and encourage greater cooperation, coordination and planning** between the various agencies that currently have responsibility for different aspects of child health. This would require, in many cases, interagency agreements on areas of responsibility and cooperation. Greater cooperation necessarily includes: more comprehensive and coordinated outreach about program availability; improved and coordinated systems of referral, screening and treatment; improved client tracking through the various programs which will require information and resource pooling among agencies.

2) **Remove barriers to access to health care.** Financial barriers must be overcome by supporting the simplification of Medicaid eligibility determination through the separation of cash assistance requirements from Medicaid eligibility. Expanded Medicaid coverage, at state option, up to 185 percent of poverty for children through age seven, and pregnant women, should be supported and encouraged. Other barriers to be addressed include the complex and cumbersome application process which should be streamlined for administrative efficiency. The application process should be made available at provider locations rather than at welfare offices.

3) **Invest in preventive care for all poor children.** This should

become a national priority. **Preventive care will ultimately contain costs while enhancing health outcomes. Risk assessment** tools should be developed that can identify high-risk children for case management services. Additionally, automatic enrollment in the EPSDT program would facilitate better preventive care for eligible children of all ages.

4) **Pediatrician participation should be encouraged** in all public child health programs. In addition, a review of the current provider reimbursement mechanisms is needed in order to encourage greater provider participation in both the EPSDT and overall Medicaid programs.

5) **Develop outreach and marketing strategies** for promotion of all aspects of wellness and preventive care among children. There should be a national outreach standard with materials that are adaptable to the needs of the various states.

CONCLUSION:

While there have been great strides made to improve children's primary care, there is still more to be accomplished. The strategy that can best address all the needs which I have discussed today is one which improves and builds upon existing systems and programs. We need to target improvements within the Medicaid program and seek out better interagency coordination in order to make efficient use of existing resources and to close the gaps in service provision which currently exist.

Additionally, there is a great need for a national outreach campaign that will stress preventive and well-child care among the general population. We must make every effort to ensure the health and safety of this nation's most valuable resource, our children. They are a sound investment for the future.

Thank you for the opportunity to testify here today. I will be happy to answer any of your questions.

WILLIAM A. NEAL, M.D.

It is a privilege to speak with you today about the health and well being of the children of this nation. I represent the National Perinatal Association (NPA), a provider and consumer organization dedicated to this goal by fostering optimal care, education, research and ordering of national priorities. As a practicing pediatric cardiologist and Professor and Chairman of the Department of Pediatrics at West Virginia University, I am honored to also represent my native state and its Land Grant Institution of higher education.

My involvement with the perinatal health care issues at the state and national level began from a rather narrow initial focus. I joined the faculty at West Virginia University in 1974 upon completion of graduate training at the University of Minnesota. As a newly trained pediatric cardiologist I was apprehensive about the ability to practice my speciality in West Virginia because of the absence of newborn intensive care unit at the University Hospital and throughout the rest of the state. I was offered and accepted the responsibility for developing such a facility at the University Hospital.

When I requested seed money for needed equipment from the federally funded Regional Medical Program I was frankly disappointed by their response. They were not willing to fund equipment, but they would and did fund a planning grant for the regionalization of perinatal care in the state. This resulted in the formation of the West Virginia Perinatal Committee, a working committee with no statutory authority comprised of pediatricians, obstetricians, nurses, hospital administrators, consumers, family practitioners and health planners from throughout the state.

The result was development of an integrated system which fostered cooperative efforts among the tertiary centers so that they would provide uniform outreach education to every hospital in the state with an obstetrical service; a system which would standardize the level of care provided by each hospital, as well as indications for maternal and neonatal transport; a system which included the implementation of ground and air transport of high risk infants and mothers funded by the State Health Department by legislative line item; a system which provided seed money for creation of a badly needed tertiary care facility in the southern part of the state, and secondary centers in strategic location.

I elaborate on this significant development for a reason: It worked! Cooperative effort by the various sectors of our state to forge a rational system to address a problem was effective beyond expectation. Neonatal mortality in West Virginia plummeted more rapidly than in any other state to slightly below the national average. Physicians, nurses and educators working within this state system were called upon to provide leadership at the regional and national level in matters related to perinatal health.

Effective political leadership and State and Federal agency support were vital to the success of this effort, beginning with the thoughtful decision of the Regional Medical Program to look beyond short term needs. Was it divine providence that the very first premature infant to be transported to the University Hospital by the new system was the grandson of a state legislator: Whether or not this was the case, line item budgeting of the system was the immediate result. The expansion of the statewide program was later funded by Title V Infant Intensive Care Funds. We received written commitment for the continuation of funding by then Governor Rockefeller. Governor Rockefeller showed great leadership toward the end of his second term by taking the bold initiative to divest the University

Hospital from direct state control so that a state-of-the-art facility incorporating a Children's Hospital within a hospital could be constructed. This truly magnificent facility will be ready for patients next month. Mr. Rockefeller has provided us the chance to provide exemplary tertiary care for our citizens. He has done his part. My part is only beginning: that is to further reduce the still unacceptably high perinatal mortality and morbidity in West Virginia.

As we are well aware the United States ranks last among industrialized nations in the percentage of our infants who survive beyond one year of age. If we are to correct this matter, if we are to decrease infant mortality to its-irreducible minimum, every woman in this country must have not only uniform access to prenatal care, but every woman must in fact *receive* prenatal care beginning in the first trimester. I submit that the issue of access must be federally mandated and funded. Implementation of a workable system to accomplish universal prenatal care must be developed and administered by state government.

Therein lies part of the problem. In reality we have 50 different Medicaid systems with different priorities. The economic and social characteristics of each state are different. The economic capacity of each state to appropriate funds eligible for federal match is highly variable. I am sad to report that the Medicaid system in West Virginia is virtually bankrupt. Bankrupt though we may be, we are not despondent nor have we given up the fight.

Medicaid is doing all it can within its limited budget to extend eligibility criteria for women. The Centers for Disease Control is providing funds for a pregnancy risk assessment program, referred to as PRAMS. The Robert Wood Johnson Foundation has awarded 1.2 million dollars to establish a case management system. The challenge to West Virginia, indeed every state, is to see that these funds accomplish their intended purpose: the documentable incorporation of every pregnant mother into the prenatal care delivery system. No exceptions. We must guard against excessive administration at the expense of actual health care delivery.

Such is our responsiblity at the local level. What is the responsibility of the Federal government?

Our elected leadership must first establish participation in prenatal care as a national goal. To suggest that the same order of commitment this country devoted to placing a man on the moon is called for may sound melodramatic. But is it: The health of our children is a gauge of the moral fiber of our society. They are our future.

It makes economic sense as well. Every dollar spent upon this preventive measure will save more than three dollars otherwise required for newborn intensive care. If one adds the cost of long term disability resulting from no prenatal care the savings become enormous.

I had intended to raise other issues related to maternal and child health care for your consideration: the potential for total disruption of already established regionalized systems of perinatal care by alternative care delivery programs; the potentially destructive and costly competitive environment created by prospective reimbursement and an oversupply of physicians; the liability crisis as it effects obstetrical care in this country; the problem of catastrophic and chronic health care for children; and finally, the threat to tertiary hospitals, especially rural ones, resulting from the problem of uncompensated care and technical problems with Medicare and Medicaid reimbursement. In the interest of saving your valuable time I will leave these issues for discussion by my capable colleagues here today.

My message shall remain simple. Every woman in this country must receive prenatal care as a preventive health measure if we really intend to further reduce infant mortality and morbidity. If I were you, I would ask: Will it work? The answer is yes. European countries have proven it. As a fiscal conservative I ask myself: Can we afford it? The answer is always the same. We cannot afford not to invest in the future of our society.

A prominent child health advocate, and good friend of mine, recently pointed out, "This is basically not a medical problem. It is a social problem with medical consequences."

I am grateful for your attention.

ELLEN PEACH, RN, MSN

I am Ellen Peach, currently a family nurse practitioner at Virginia Commonwealth University. I appreciate the opportunity to testify about some of the issues confronting the health of rural mothers and babies.

For the past several months, I have been a consultant to the National Rural Health Association on a study funded by BCHDA designed to explore the health care systems of four rural counties in the United States who had decreasing infant mortality rates over the past 15 years. The task was to identify the changes, if any, that had occurred in the health care systems of these small counties and to suggest possible variables that might have contributed to the improvement of the infant mortality rate.

The Problems--Highlights

Across the country, rural areas continue to struggle with significant challenges to the delivery of maternity and infant care to their residents. According to data published and prepared by McManus and Newacheck for the Rural Health Research Agenda Conference (2/88), we know that the fetal death rate (stillbirths) for black women in non-metro areas is higher than that in metro areas by 25%. (The fetal death rate is one indicator of prenatal and intrapartum care.) Only 50% of non-metro women less than age 20 were likely to obtain adequate prenatal care (first trimester). Only 57% of southern black women of all ages through the child-bearing years were likely to have received first trimester prenatal care. For an unmarried rural woman over age 25, the likelihood that she will receive adequate care is one-half that of her urban counterpart. Fewer non-metro women had access to technological advances in obstetrics such as ultrasound and fetal monitoring during labor.

In Arizona, 30% of rural physicians previously offering OB services have discontinued their obstetrical care, primarily because of malpractice issues. In 1970, 14% of physicians practiced in non-metro communities; today, it is 13% although there has been an increase in physicians in office-based practices. The gap between physicians in metro and nonmetro areas remains the same as it was in 1980.

Financial barriers to care also exist for rural mothers and children. Rural families are less likely to be privately insured and are more likely to be making out-of-pocket payments for medical care. Families in rural states are more likely not to qualify for Medicaid because of restrictively low income eligibility thresholds. Hopefully, the SOBRA and COBRA options will assist these families.

Rural hospitals face declining revenues. They also face declining numbers of registered nurses available to staff the hospital and are in competition with other facilities who can pay more. One consequence of this shortage is on mothers in labor who need skilled nursing care and early identification of problems should they occur.

Data on rural health problems affecting maternity and infant care is notoriously hard to obtain, and, in many cases, absent. There is no mandated national reporting system for Title V programs, a critical lack for rural areas, since much maternal-child care delivery in rural areas is delivered by these programs. Data sets vary from year to year, making comparisons difficult. Any meaningful assessment of problem or change must have an adequate data base from which to work.

Possible Variables Contributing to Improved Infant Mortality Rates in Four Rural Counties

The National Rural Health Association has committed itself to studying factors affecting the health care of rural Americans and focusing attention on those issues which are most in need of change.

The four small counties that the National Rural Health Association studied this year were all less than 35,000 in population but larger than 10,000. These counties are located in Louisiana, Texas, Montana, and South Carolina. They were chosen for their geographic and ethnic diversity as well as their rurality. All of these counties have had an improvement in their infant mortality rates over 15 years.

No miracles happened here. In some cases, the maternal-infant health status indicators merely changed for the better but still do not reach the 1990 objectives. There is still much room for improvement in each of these counties, but there has been improvement.

The following changes occurred in the past 10-15 years in the counties studied:

In three counties, there has been placement of publicly-supported physicians or a certified nurse midwife or nurse practitioner over the past decade.

-- In Clarendon County, South Carolina, the physician with the Rural Health Initiative Project is placed as part of the South Carolina medical scholarship pay-back system. The first day that he opened the practice, there were poor, expectant mothers literally waiting at the door.

--In Roosevelt County, Montana, there are 2 National Health Service Corps placements and the Indian Health Service (PHS) physicians who provide care to a majority of the county residents. A certified nurse midwife did the bulk of PHS deliveries for several years until he left 2 years ago.

—In Caldwell County, Texas, the two young family physicians who are providing most of the in-county obstetrical services are part of the Texas medical scholarship pay-back program. One has served his obligation and has decided to stay. The other might.

In three counties, some arrangement for in-county obstetrical consultation has been made and/or obstetricians have actually been attracted.

--In Evangeline Parish (population 35,000), two obstetricians are now practicing full-time. Both came as a result of successful recruiting by a small, private non-profit hospital in the parish.

--Also in Evangeline Parish, the obstetrician who provides care to medically indigent pregnant women at the Health Unit is part of the state-supported Charity Hospital system in that state and travels into the Health Unit from University Medical Center in Lafayette. (Louisiana's public health system is undergoing severe strain because of the state budget crisis.)

--In Roosevelt County, an obstetrician comes in from Williston, ND, on at least a monthly basis to consult with family physicians who provide the OB care in the county. Ultrasound videotapes are sent to an OB radiologist who also makes periodic visits into the county. The providers and hospitals in this small county (population 11,600) are jointly exploring and planning for the possibility of acquiring a full-time obstetrician who would be shared among the hospitals, private providers, and the public health service system.

--In Texas, an obstetrician from a neighboring county comes into the health department to see indigent women who are high risk and in need of care.

Perinatal transport systems and training exist.

--In Clarendon County, SC, the Level I hospital had nursing staff trained at the regional referral center in both early identification of intrapartal problems and also in newborn resuscitation. Transport teams come to the hospital from the regional centers in the event of crisis.

Similar training and transport arrangements exist in two other counties in the study.

There is high utilization of WIC services and low-income pregnant women identify WIC as the first service to seek.

--Counties studied have a very high percentage of WIC need met among both pregnant mothers and infants, e.g. Roosevelt County, MT, has met 66% of its WIC need (Montana state average - 40%), and Clarendon County, SC has met a staggering 90% of its WIC need.

Program boundaries are porous.

--In Clarendon County, SC, WIC visits during pregnancy are also used to enroll or refer women into maternity care and are used to assess women for risk of preterm labor.

--In Evangeline Parish, any visit for any reason to the Health Unit by an infant initiates a standard Improved Infant Health visit.

--In Roosevelt County, the private, PHS, and NHSC physicians share call, consults, and coverage on a regular basis.

Systems of case tracking and management have either evolved or have been formally implemented in some of the counties. Data is collected.

--Roosevelt and Clarendon Counties, and Evangeline Parish have implemented tracking systems for prenatal patients and infants who are part of the PHS or health department system. They all have postpartum home visiting and/or phone contact within the first week after delivery for those women who are part of the PHS or health department system.

Community concern and leadership about the problems of maternal-infant care have developed.

--In Evangeline Parish, the hospital administrator engineered the start of an RHI in 1979 and another rural satellite clinic two years ago. As mentioned previously, two OBs were recruited as well as anesthesia support, and a pediatrician. Fetal monitoring and ultrasound is available for pregnant women.

--In 1979, in Clarendon County, a community Perinatal Task Force was started out of broad-based concern for the high infant mortality rate in the county. The Task Force developed an intensive perinatal education program which swept through the schools, churches, and garden clubs and won an award in 1982 for innovation and dedication in the area of public health.

Interagency Coordination and Cooperation

--In three of the counties, many services are colocated. For example, in Poplar, Montana, the Indian Health Service Clinic is to the left, the hospital in the middle, and the community health center to the right in one block. Proximity can (although not always) facilitate cooperation. It certainly eases the burden on rural poor mothers who lack for transportation or must arrange childcare.

--In Clarendon County, the Department of Social Services sees the issue of infant mortality as its problem as well as the health department's problem. It facilitates Medicaid enrollment, provides transportation to high risk maternity patients who must travel to Level II or III centers for obstetrical visits, and shares a clerk with the health department.

There were individual or collective efforts to see that mothers and babies that needed care were somehow channeled into care.

--In Clarendon County, the two local family physicians who provide contract OB services to the Health Department discount their OB services to indigent women who do not qualify for Medicaid.

--The two family physicians providing care in Caldwell, County, Texas, take patients who may never be able to pay and are not eligible for any other form of insurance.

Low-risk OB services provided by public health nurses were present in three counties and supported by both the system and consulting physicians.

CONCLUSION

These are some of the changes that have occurred in the counties studied. One cannot attribute cause and effect; one can only suggest these as variables. Further studies need to be done...soon.

The sense that I have after getting to know these counties is one of cooperation, ingenuity, patchwork programming, compassion, leadership, and hard work.

There are still women who do not have any means of paying for maternity and infant care. Teen pregnancy is either not addressed or just being addressed. Schools are not used effectively in early identification of pregnant adolescents in the counties studied. Rural systems are fragile. Evangeline Parish (Savoy Medical Center) had to pay for temporary OB coverage for a year when one OB left or risk an entire OB delivery system. The loss of even one physician who does OB can erode a rural community-based system within months. Residents must travel elsewhere.

Good Morning. I am James Perrin, M.D., director of general pediatrics and ambulatory care, Children's Service, at Massachusetts General Hospital and am pleased to be here today on behalf of the American Academy of Pediatrics. The Academy represents over 34,000 pediatricians dedicated to improving the health and welfare of our nation's infants, children and adolescents.

At the outset Mr. Chairman, I want to commend you and your committee for your tireless advocacy on behalf of children. Despite the specter of punishing deficits, through your leadership, this committee has successfully fashioned significant improvements in the Medicaid program for mothers and children each year since 1983. This committee is also responsible for creating the Maternal and Child Health Block Grant and has advocated important reforms to many other child health programs in the past.

Nevertheless, despite your best efforts and those of your colleagues, there remains more promise than progress in these vital programs.

- By 1984 Medicaid reached only 38 percent of the poor, down from 65 percent a decade before. This drop followed 12 years of rising enrollments since the program's creation in 1965. Overall enrollment in Medicaid has declined in recent years from a high of 23 million recipients in 1977 to 21.1 million in 1984.

- The rate of children who are uninsured in this country is rising. It is currently estimated that between 11 and 16 million children through age 21 are uninsured all or at least part of the year. The recent OTA report "Healthy Children: Investing in the Future" states, "In 1980, the percentage of children under age 13 who were reported to be uninsured was 17%; by 1984 the rate has increased to 18%; and by 1986, it was 19%. 61% of all children under age 13 who were reported to be uninsured were from either poor or near poor families. Thus, in spite of recently enacted Medicaid expansions available to the states targeted to poor children in younger ages, lack of financial access to the health care system has actually increased rather than leveled off or decreased.

- The infant mortality rate in this country - the accepted benchmark of a nation's child health status - is increasing. Indeed, little progress has been made in recent years to reduce the United States infant mortality rate which continues to rank 17th among industrialized nations behind East Germany, France, Ireland and Spain. 40,000 infants die each year in the United State before their first birthday (more than 1 percent of all babies born in this country). Many of these deaths could have been prevented by receiving adequate prenatal care, which is the single most important factor in preventing infant mortality. 81% of privately insured women received prenatal care, compared with only 31% of those on Medicaid. Although a number of reasons are cited why women fail to receive prenatal care, lack of medical insurance and physicians who will not accept Medicaid patients are among those most often cited.

- The teen age pregnancy rate in this country is one of the highest in the world and is rising. US girls under 15 years of age are five times more likely to give birth than in other developed countries. Most pregnancies among teens are unintended and infants born to these mothers are at greatly increased risk.

Although the relationship between the lack of financial access to the system and health status is unclear, there is unambiguous evidence that mothers and children without health insurance do not use preventive, chronic and acute care as much an insured children (Rand Health Insurance Experiment). Thus, while a number of factors impact children's access to care, financial barriers are the most significant.

Mr. Chairman, you, I, the members of this committee, the Academy, other child advocacy groups represented here today and those not present, are all responsible for the state of the health of our nation's children and the inequities in the system.

Many of us have appeared before this committee and similar forums in the past. On each occasion, we dutifully review the statistics and present a series of legislative recommendations. Indeed, we probably could have resurrected much of that testimony for our presentation today. After each, you and the other dedicated members of this body try to enact those proposals which are good policy, feasible, and in the current climate, cost effective. But our carefully written statements, lofty rhetoric and good intentions aside, it is time to realize this approach is not working. After a decade of incrementalism, the state of our children's health has not improved commensurate with our resources, and our children's health care system is as fragmented as ever. Nor should we be surprised by this reality. Given that there is no inherent design or "system" of child health care financing in this country, efforts to weave together a coherent plan from the patchwork of programs have failed. Further, if past experience teaches us anything, it is unlikely that these problems will be resolved in the foreseeable future if we pursue current strategies. The enormous variations state by state in the Medicaid program -- which are inherent to its design -- make the program virtually ineffective for many children. Even with a strong federal mandate, it is unlikely that employer -based insurance programs will ever appropriately cover the panoply of services required by children and families with special needs, an ever-growing portion of our population. In short, incrementalism is a failure and our children deserve better.

I am pleased to tell you, Mr. Chairman, that at its recent Executive Board meeting, the Academy voted to make ensuring children's access to health care our main priority for the upcoming years. To that end, we intend to invest the time, resources and energy necessary to develop a proposal which would guarantee access to health care for all pregnant women and children. Although the specifics of such a proposal are far from being developed, the underlying principles of such a proposal are clear: that all children must have access to an array of health care benefits that will ensure their optimal health and well being; that these services should be performed in a cost effective manner that does not compromise the highest quality of care; and that these plans should be incorporated as part of a children's health policy.

The Academy plans to work closely with many of the advocates who are represented here today and keep you and your staff informed of our deliberations as we proceed. In the interim, we believe it is important to continue to support and to promote reforms to the existing child health programs, such as Medicaid and the Maternal and Child Health Block Grant, which may serve as the foundation for future efforts. The following testimony thus reviews children's access to care, including children with chronic illness and disability and catastrophic expenses and proposes specific recommendations for Medicaid and Maternal and Child Health Block Grant.

I. CHILDREN'S ACCESS TO CARE

The introduction to the Academy's report on the value of preventive care states:

> "Growth and development are the dynamic processes which distinguish children from adults and dictate periodic, continuing, individual preventive health care to assure that each person may achieve his or her optimum potential."

As such, children have a great need for primary care services and health supervision, including ambulatory care, preventive care and immunizations. Such care supports children and helps them to achieve optimal physical, intellectual and emotional growth and development and improves their chances to develop into healthy and productive adults. Early intervention can prevent disease and minimize the severity of certain disabilities.

Numerous studies have shown that preventive health care at an early age reduces the risk of acute illnesses in later years, which translates to fewer dollars spent on sickness services during an individual's lifetime. It has been found that children screened through EPSDT in Missouri were, on average, 33 percent less costly to Medicaid than other children; in Ohio 30 percent less costly; in North Dakota 40 percent less costly; and so forth. It is ironic that while Medicaid pays for such care, most private health insurance does not. Indeed, the total cost for providing all child health supervision services is less then the cost of one day in the hospital. A 1983 study conducted by the Academy with an independent certified actuary and a major life insurance company showed that the cost for additional coverage according to the Academy's Guidelines for Health Supervision would, on average, be $2.28 per month per family, assuming a 100% utilization rate.

Clearly the cost of children's health care remains a spectacular bargain when compared with that for other age groups, particularly when one considers the number of years of improved functioning that can be bought at such a small price.

In spite of this evidence, most insurance companies discriminate against children by denying coverage for services they need and use, e.g. ambulatory and preventive services. Children are hospitalized with 1/4 the frequency of adults, but instead use 2.5 times the ambulatory services, particulary when they are young. Children's health expenses are low, approximately $500 per capita year (under 17 years) compared with $1,485 per capita year (ages 45-64) and $2,721 for persons 65 and older. (These numbers are based on 1980 NMCUES data updated for 1984 dollars.) With the exception of HMOs and some group practices, most insurors reimburse for hospitalization for acute care. As such most children are uninsured or or inadequately insured.

POPULATION IN NEED - UNINSURED AND UNDERINSURED

Children as a group are disproportionately uninsured. Nearly one American child in five has no coverage and one third of the uninsured are children. The chance of being uninsured is 37 percent higher for a child than an adult. To put these numbers into context, there are approximately 37 million uninsured individuals of whom:

- 65 percent were employed workers and their dependents (24.3 million);
- 32 percent (11 million) were children age 18 or under;

Of the uninsured children, 64 percent (7 million) lived in a family headed by someone who was also uninsured while 29 percent (3.2 million) lived in a family with employer-based insurance coverage.

National Medical Care Utilization and Expenditure Survey (NMCUES) data from 1980 suggest that an additional 7 million children are only insured for part of the year. Gaps in coverage are particularly large for children between the ages of 0 and 2 years of age, and for adolescents and young adults. Thus, while children represent only 29 percent of the population, they represent, at times, almost half of the uninsured. Children from poor or near poor families (between 100 percent and 150 percent of Federal poverty guidelines) were less likely to have health coverage than their more affluent counterparts. Roughly one third of all poor children under age 13 are uninsured, according to the recent OTA analysis of census data.

These data concern us as pediatricians because the lack of insurance is denying access to medically necessary care, including preventive services recommended by public health agencies, for many children. Numerous studies have shown that uninsured children are far less likely to seek medical care - even when sick - than those who are insured. These children are frequently denied access to care and a larger portion of their expenditures for health care must be spent out of pocket. Further, because they do not receive preventive care and routine health supervisions, they are more likely to incur catastrophic expenses -- in relative as well as absolute terms.

Another NMCUES analysis shows that among low-income children, those without Medicaid were 33 percent more likely not to visit a physician compared with those with Medicaid coverage. Those low-income children without any Medicaid coverage who also had no private insurance coverage were 50 percent more likely to have no medical visits. The analysis also shows that low-income children with Medicaid or private health insurance were likely to see a physician more frequently than those without such coverage. For example, the average number of visits per year for low-income children covered by Medicaid, 2.9 per child, exceeded the average for uninsured low-income children, 1.8 per child.

Even children with health insurance may not be adequately covered for primary care services. Many plans limit benefits, including preventive care, and limit the amount, duration and scope of benefits. Inadequacies in coverage are particulary true for children covered through Medicaid -- where differences in covered services as well as the amount, duration and scope of coverage vary dramatically state by state. Roughly one half of all poor children are covered by Medicaid. Of the 12.9 million children estimated to be in poverty in 1986, 6.7 million were covered through Medicaid.

II. CHILDREN WITH CHRONIC ILLNESS AND DEVELOPMENTAL DISABILITIES AND THOSE WHO INCUR CATASTROPHIC HEALTH EXPENSES

Financing health care for children with special needs is as complex as the health problems of these children. Yet, developmental disability and chronic illness are growing problems among children and adolescents and their health care utilization and expenditures have increased accordingly. Children with disabilities are twice as likely to be hospitalized and spend four times as many days in the hospital as nondisabled children. Disabled children visit physicians five times more than nondisabled children and use six times as many allied health services and twice as many medications. Although major national health financing programs exist for very low-income persons (Medicaid) and for the elderly (Medicare), there is no comparable national program or commitment to children with special health care needs.

Recent prevalence estimates suggest that at least 10 to 15 percent of all U.S. children suffer from a chronic health impairment of varying severity (Gortmaker and Sappenfield, 1984). Most of these children have mild conditions which interfere to only a limited degree with their usual daily activities. Nevertheless, 2 to 4 percent of all children currently face severe chronic health conditions that create special challenges to the family and burdens for the child as he or she grows up. During the last two decades, the number of children with activity limitations has nearly doubled (Newacheck et al, 1986). Researchers believe this increase is the result of improved survival as well as increasing identification resulting from enhanced awareness of chronic illness and disability as important health problems. Recent data show, in fact, that 80 percent of children with the most common severe chronic conditions (e.g., cystic fibrosis, spina bifida, congenital heart conditions, cancer, and muscular dystrophy) now live to adulthood. (Hobbs, Perrin and Ireys, 1985)

A subset of children incur catastrophic health expenses, defined as a child whose family's out-of-pocket medical care costs reach a maximum of 10 percent of their annual adjusted gross income. For children who live in families with incomes less than the federal poverty line (one in five), the out-of-pocket threshold should be less than 10 percent, as a smaller proportion of family income for medical care could create catastrophic circumstances for their families. This also includes infants who require neonatal intensive care and children who incur catastrophic expense because of accidents or injury.

All available empirical evidence indicates that the incidence of children in need of financing for catastrophic health care to supplement existing private and public insurance is relatively small in absolute terms and proportionately much lower than that of the adult population. According to the National Medical Care Utilization and Expenditure survey, of the 70 million children in this country, only 0.6 percent (421,000) had out-of-pocket medical expenses greater than 10 percent of their family's income in 1980.

Children (and families of children) with developmental disability and chronic illness and those who incur catastrophic expense have common interrelated psychosocial, medical and educational needs which go beyond those experienced by healthy children or those with acute illness. Some service needs relate to the specific nature of the child's health condition;

most, however, reflect the fact that severe chronic illness or disability of any type creates special needs for the child and family (Pless and Perrin, 1985). Additional health-related needs may include more frequent and higher-intensity use of specialty and primary care medical services; services from related allied health professionals (such as physical, occupational, speech and language, or respiratory therapy); mental health care services; care coordination activities; developmental assessments; home care services from nurses and allied health professionals; special equipment; special clothing, supplies and diet; home modification; transportation; special child care and respite services; and educational, vocational, and financial planning to diminish the adverse effect of the illness and its treatment on the child and family's growth, development and future productivity. (Please see Table 1 for a listing of health related and other service needs.) Most families whose children have chronic illness or disability have no need for all these services. However, these services should be available to all families with chronically ill children.

CARE COORDINATION

The coordination of medical care through care coordination results in quality care and efficient, cost-effective use of health care resources and is extremely important. Children with chronic illness and those who incur catastrophic expenses, whether through a privately-funded or publicly-funded program, should have access to care coordination services.

Families of children with special needs find themselves the victims of uneven service. The nature of human service programs themselves, each with its own planning, reporting and evaluating systems, leads to fragmented service delivery. The complexity of each of these major service delivery systems necessitates cooperation of services across systems (Magrab and Elder, 1980). There are great inefficiencies, opportunities lost, and unnecessary costs incurred when there is not integration of the needs of individuals. Care coordination provides an on-going plan designed for each child specifying medical, nursing, equipment, educational and therapy needs. Care coordination entails continuous monitoring, quality assessment of services, and constant revisions of the plan in response to the child's changing needs and developmental status and the families financial and emotional resources.

Properly constructed care coordination can stop duplication of services, decrease wasted services and avoid unnecessary expenses. The Coordinating Center for Home and Community Care Inc., a case management agency for the Medicaid Model Waiver program in Maryland has documented a dollar saved for every dollar spent by Medicaid during their first 34 months of operation. Servicing 50 medically-fragile children, the total spent for comprehensive services was 3.1 million dollars. Had these children not received community-based services under the guidance of service coordination, the total price would have been 6.2 million dollars.

Care coordination has two components. It includes the coordination of medical care, and the process of assisting families to gain access to, financial support for, and coordination of comprehensive services at the community level. These two components (medical care coordination and community-based service coordination) must both be included in a unified, family-focused, outcome-based plan. The plan must identify all health and related needs, the recommended course of treatment, resources available to pay for care, and methods for filling the gaps in needed services and coverage.

For the medical care coordination component of care coordination, the child's primary care pediatrician is often the best suited by training and experience to be the case manager. He or she can thus ensure the quality and continuity of medical care. Coordination of the wide array of services at the community level, the second component of case management, may be done by the child's primary care pediatrician, social worker, public health nurse, or another professional. In cases in which the pediatrician does not direct community service coordination, it is essential that the case manager actively involve the child's primary care pediatrician. Appropriate reimbursement for the provision of case management services is the responsibility of the public or private insurer paying for the care being managed.

PROBLEMS OF THE CURRENT SYSTEM

Current provision of child health care services is based upon several mechanisms: private and public health insurance, out-of-pocket payments by families, donated professional services and philanthropy. Approximately 86 percent of chronically ill children currently have access to varying degrees public or private health insurance.

These mechanisms, however, as inadequate as they are for most children, are rarely adequate to finance the special health care needs of children with chronic illness and those incurring catastrophic expenses. In addition, rarely are these funding sources coordinated. Consequently even when the full spectrum of health-related services is available in a community, services are not used appropriately -- risking less than optimal outcomes, prolonging morbidity and increasing long-term societal costs.

Private insurance fails the child's family because it is often inaccessible, unaffordable or insufficient to finance the preventive and comprehensive care required. Most private insurance comes as an employment benefit. Private health insurance is rarely accessible to unemployed or seasonally-employed parents. For others, individual coverage may be available but family coverage is lacking. Frequently, children are denied coverage because of a "preexisting" condition. Benefit packages typically do not include the full range of services needed by children with long-term health conditions. In addition, the high costs of care required by some children commonly exceeds maximum annual or lifetime limits, and coverage is lost.

Medicaid is the most important public insurance program affecting children. Although there is tremendous variability in program implementation from one state to another, common shortcomings important to the chronically disabled child include: failure of many states to cover an appropriate array of mandatory and optional services; spend-down requirements for medically-needy families which tend to make and keep them financially destitute; restrictions on the type, setting and providers of services which interfere with accessibility and continuity of care; insufficient use of the federal provisions of the Early and Periodic Screening, Diagnosis and Treatment program (EPSDT) allowing supplementation of limited Medicaid benefits; and rigid eligibility criteria which can cause sudden loss of benefits and disruption of treatment continuity when minor and temporary changes occur in family income. Additionally, inadequate and delayed Medicaid reimbursement for services often discourages participation by many of the most appropriate and accessible health care providers.

The Title V Maternal and Child Health Block Grant Program (which includes Services for Children with Special Health Needs, formerly called Crippled Children's Services) is also a public program. Unlike Medicaid, however, these state programs are designed to provide or arrange services for children with specific long-term illnesses. In the past two decades, funding for Title V has not grown in proportion to the population needing services and has been overshadowed by growth in other public programs, especially Medicaid. State agencies have wide latitude in how they implement the program, resulting in great variations in administration, eligibility, and covered services from state to state. (Ireys, Hauck, and Perrin, 1985)

Ultimately, families become the payors of last resort for most underinsured and uninsured care. To obtain needed services without delay and minimize out-of-pocket debt, families in conjunction with a care coordinator must negotiate and coordinate multiple funding sources. Understanding the complexities of these multiple sources (many of which change criteria and policies frequently) remains exceedingly difficult.

PRINCIPLES

Solutions to the problems of providing and funding comprehensive health care services for children with chronic disability must involve every aspect of today's public and private resource base. The AAP's objective is to assure that needed services exist and that financial barriers to those services are eliminated by creating a community-based, care-coordinated system of quality services in a public/private partnership that protects families from catastrophic medical expense.

Therefore, all health care strategies for children with chronic illness and disabilities must:

1. Assure access to needed health care services for all children without regard to race, religion, national origin, economic status, place of residence, health or functional status;

2. Cover a broad array of services that are comprehensive (including

ambulatory, hospital and long-term care equipment and supplies), continuous, cost efficient and to the extent possible, community-based;

3. Provide for a system of case management or care coordination;

4. Assure quality through adherence to established standards of health care;

5. Actively seek the participation of families in the development and implementation of their child's care or treatment plan;

6. Include the child's primary pediatrician as an integral component;

7. Provide reasonable reimbursement to the care provider for the time expended in delivery of all necessary components of the child's care to ensure an adequate supply of providers; and

8. Be affordable to both family and society, and protect family income and assets against catastrophic medical expenses by adopting a catastrophic insurance mechanism.

Each child with a chronic illness or disability who requires health care services over a long period of time should be sufficiently insured to provide for:

o A comprehensive plan of care or treatment specific to the child's and family's needs. The plan should integrate all aspects of care -- including health, social, educational and vocational.

o Care coordination to ensure that the family and child's health needs are met, interagency responsibilities are coordinated, services are delivered in a cost-effective manner, and all available financial resources are equitably utilized.

o Quality assurance and followup. Mechanisms must be available to monitor the care provided, assure efficient use of resources, and provide continuity of care on a long-term basis.

IV. PROGRAM RECOMMENDATIONS

The following makes recommendations for the Maternal and Child Health Block Grant and the Medicaid program - the two main child health financing programs under the purview of this committee. The Academy believes, however, any true resolution to the complex issues affecting children's access to health care will involve a public/private sector partnership. As such we have also developed recommendations for private insurors, employer-based plans and state level activities.

A. MATERNAL AND CHILD HEALTH BLOCK GRANT

As you know, the Maternal and Child Health Block Grant (Title V of the Social Security Act) is the only public health service program which is devoted exclusively to meeting the needs of mothers and children. As such the MCH Block is a unique and important program whose efforts and initiatives must be strengthened and reinforced.

The purpose of the MCH Block is to enable each state to assure mothers and children access to quality health services, reduce infant mortality and incidences of preventable diseases and handicapping conditions among children, provide rehabilitation services for blind and disabled children under the age of 18 and provide otherwise unavailable services for children with disabilities and chronic illnesses. As such, the Block has a dual focus -- to serve the primary and preventive care needs of all children and mothers and also to help children with special health care needs. Clearly, these are worthy goals.

The program is up for reauthorization next year. The Academy has begun to work with a number of child advocacy groups to develop recommendations which will strengthen and enhance the role of this program and its ability to meet the needs of the mothers and children it is designed to serve. Indeed, the medical environment has changed dramatically since the enactment of this block, both in areas of medical technology and treatment and financing for an array of needed services. It is important that we examine the design and ability of this program to meet the complex needs of today's children and their families -- needs that involve a range of services from health, education, social services and other areas. The block must be assessed with respect to its responsibility for children and families for preventive, sick and catastrophic care coordination.

Although it is premature to discuss the details of any such proposal, several concepts are clear. First, there is a need to ensure that the needs of mothers and children are carefully assessed and a plan developed to meet those needs. At a minimum we believe these plans should 1) identify the unmet health needs of mothers and children; 2) identify availability of resources for unmet needs; 3) assess children's access to care, including the types of services they are receiving the payment vehicle; 4) set specific and measurable goals for improving services and health outcomes; 5) specify steps to be undertaken to attain these goals; and 6) specify steps to coordinate efforts among providers and relevant federal supported programs, such as the MCH Block, WIC, EPSDT, family planning, PL 99-457 and Medicaid. Second, there is a pressing need to improve the data collection function through the block -- the number of types of women and children who are being served; their diagnostic conditions; who is paying for their care; and an assessment of unmet need. Third, we support strengthening the accountability provisions in the block -- where dollars are being spent and who is receiving services. Fourth, we believe funds should be made available to ensure that families with children with special health care needs have access to care coordination. Finally, we support mechanisms to improve the coordination of this program with all other state child health programs, for example, Title XIX, Title X, the lead agency under PL 99-457, SSI and WIC, to name a few. The fragmentation of child health programs at the state level continues unabated -- leading to further duplication and fragmentation of services.

In addition, we recommend the Secretary of the Department of Health and Human Services be required to report each year to Congress on the state of our children's health, based on state data. This report should assess children's access to care, including children who are receiving care, the types of services they are receiving, who is providing and financing their care -- as well as unmet needs. Each year the Secretary should set specific and measurable goals improving services and outcomes and steps to attain these goals.

The Academy will continue to work with a consortium of child advocacy groups to develop these concepts into specific recommendations for consideration next year.

B. EXPAND AND IMPROVE MEDICAID

While the incremental improvements in allowable Medicaid benefits and eligibility over the past years has helped, the enormous variations and limitations in state coverage have resulted in nonexistent or ineffective programs for many children. The present system, by offering better health care coverage to a child because of geographic location, is inequitable and discriminatory. The Academy recommends the following:

1. Mandate eligibility for all pregnant women and children through age 21 years regardless of family structure, whose family income is less than 100% of the federal poverty level.

2. Permit states to extend eligibility to children through age 21 whose family incomes are between 100-200% of the federal poverty level. Allow states to charge an income-adjusted Medicaid premium of no greater than 10% of that family income greater than 150% of the poverty level.

3. Mandate state extension of Medicaid to children with chronic illnesses in families with incomes between 100-200% of the federal poverty level and those who incur catastrophic expense. These children should be entitled to an enriched package of benefits.

4. Permit optional purchase of Medicaid for families with chronically ill or disabled children whose incomes are greater than 200% of the federal poverty level, where no other source of health insurance exists. The premium charged should be no greater than 10% of family income. Coinsurance obligations, assessed on a sliding scale basis, may be considered.

5. Mandate Medically Needy Programs in all states.

6. Assure that all children with disabilities receive EPSDT services, thus rendering them eligible for enriched services under Title XIX even if these services are not provided for other state Medicaid beneficiaries.

7. Improve reimbursement rates to health care providers to enhance access to care

A word about the last recommendation. As has been made dramatically clear by the current crisis in obstetrical services, reimbursement problems affect women and children's access to care. As the committee examines these problems we encourage you also to review the problems associated with children's access to pediatric care. As you know the Academy's advocacy has always focused on improving eligibility for Medicaid, the benefits package and amount, duration and scope of services. These continue to be our priority concerns. Nevertheless, reimbursement problems continue to pose a barrier to children accessing needed care and should be addressed.

The Academy is eager to work with your Committee to enact many of these reforms and create an improved child health care financing system. We thank you for your continued support and interest in these areas and look forward to our future efforts.

STATEMENT OF ARNOLD C.G. PLATZKER, M.D.

Mr. Chairman and members of the Committee, I am Dr. Arnold C.G. Platzker, Head of the Division of Neonatology and Pediatric Pulmonology, Childrens Hospital of Los Angeles and Professor in the Department of Pediatrics at the University of Southern California School of Medicine. Today, I also represent the American Lung Association and its medical section, the American Thoracic Society.

The American Lung Association is the nation's oldest voluntary health organization. Its mission is the prevention and control of all lung diseases. This mission is carried out through programs in research and training, education of both the public and the health care professional, and public advocacy. Since its founding in 1904 as the organization dedicated to the attack on tuberculosis, the major health problem of that era, the ALA has provided leadership in the development of rational, scientific approaches to the management of significant, disabling lung disease.

The manifestations of lung disease and dysfunction among children are exceptionally varied. Lung disease accounts for the majority of disability and death among persons under 17 years of age. The lung is the most vulnerable organ to the acute and recurrent injury in the developing infant and child. Episodes of pulmonary disease account for more hospitalization days lost from school and disruption of family function than disorders involving any other organ system. While asthma and cystic fibrosis have long been recognized as significant causes of chronic and acute disability in childhood, the range of pediatric lung disease also encompasses acute lung injury from the neonatal period to adolescence; the chronic medical sequelae of early acute lung injury; congenital malformations of the thoracic cage and thoracic structures; infectious, toxic, hypersensitivity and idiopathic forms of pneumonia; and disorders of the control of ventilation, called apnea.

MAGNITUDE OF THE PROBLEM

Chronic pulmonary diseases affect approximately 27 percent of children under the age of 17 years, i.e. 17.4 million children. Furthermore, this form of lung disease category accounts for 29 percent of all hospitalizations of children under the age of 15 years. The following tables describe the significance of chronic lung disease in the pediatric population. ALA's commentary today will focus on two major categories: chronic obstructive pulmonary disease (reactive airways disease); and conditions of the newborn infant resulting in respiratory failure and chronic respiratory sequelae.

MORBIDITY (1986)

	Hospitalizations	Length of stay
Asthma	158,000	3.2
Pneumonia	194,000	4.6
Influenza	10,000	3.0
Neonatal Diseases	48,000	17.8
Cystic Fibrosis	7,000	11.9

MORTALITY (1985)

	< 15 yrs	< 1 yr	1-4 yrs	5-14 yrs
All Causes	56,302	40,030	2,339	8,993
Pediatric Pulmonary Diseases	14,936	14,251	323	362
Neonatal Diseases	8,141	8,106	32	3
Reactive Airways Diseases	269	108	50	111
Pneumonia and Influenza	1,054	705	219	130
Cystic Fibrosis	157	17	22	118

HOSPITALIZATIONS (1986)

	Discharges	Days of Care
Neonatal Diseases	48,000	857,000
Reactive Airways Diseases	259,000	887,600
Pneumonia and Influenza	204,000	895,400
Cystic Fibrosis	7,000	83,000

Chronic Obstructive Airways Disease

Chronic obstructive airways disease (reactive airways disease) is the most common manifestation of lung disorder in childhood. The underlying cause of this condition includes acute airways injury, recurrent infection, recurrent aspiration, viral trachael and bronchial infections, inhalation of environmental toxins, and airways sensitization to inhalent allergens. There is also evidence for the occurrence of intrinsic reactivity and increased airways tone due to imbalance of the autonomic nervous system.

Asthma is perhaps the most widely recognized form of chronic obstructive airways disease. The pathophysiology of asthma is controversial and as a consequence, the approach to its identification and management remains controversial. There is an urgency to resolve some of these controversies in that the incidence of mortality due to asthma or asthma-like disease is on the increase in the United States as well as in western European countries. The American Thoracic Society, in collaboration with other organizations, is committed to ongoing study and resolution of these controversies in order to develop more uniformly effective programs of treatment for all children with obstructive airways disease.

Asthma afflicts approximately seven percent of all children under the age of 15 years. In 1985, the prevalence of pediatric asthma was estimated to be 2,380,671 cases. Pre-adolescent males are affected twice as frequently as females. Chronic obstructive airways disease occurs in children of all socioeconomic groups, but the clinical severity may be greater in children of impoverished families. Chronic obstructive airways disease accounts for eight percent of all hospitalizations of children under age 15 years. This disease process accounts for about 4.5 million physician office visits annually.

The range of disease severity for chronic obstructive pulmonary disease in the pediatric population varies from mild respiratory difficulty from episodes of wheezing responding readily to routine bronchodilator treatment prescribed by a pediatrician, to a clinical picture characterized by chronic low grade symptoms of respiratory distress, punctuated by episodes of severe, life-threatening respiratory decompensation requiring hospitalization for intensive care.

Patients and families with the latter type of disease must be continuously aware of intrinsic and environmental factors that upset the delicate respiratory compensation maintained by a tightly controlled, highly regimented, medication plan. Such patients and their families must adopt significant alterations in the usual family lifestyle to assure that medications and treatments are always immediately available and administered on a rigid time schedule. Ordinary family activities are regularly constrained or truncated by concerns of impending respiratory instability.

Any failure to respond to subtle changes in patient condition and/or environmental conditions, may result in precipitous respiratory insufficiency requiring immediate assessment and treatment in the emergency room setting. Frequently such events are followed by hospitalization in the pediatric intensive care unit. These episodes occur repeatedly and represent high costs to family function, as well as high costs in terms of acute health care services including physician services, nursing and respiratory care in the emergency room, pharmacy services and supplies. The annual cost of treating the pediatric patient with chronic obstructive airways disease is approximately $702 million.

A key element to successful management and resolution of any chronic medical problem in the pediatric age group is access to ongoing, expert definitive diagnostic and comprehensive therapeutic care. Children with chronic lung disease have great capacity for partial or complete resolution of their respiratory illness with early identification and appropriate care. This avoids the serious longterm disability resulting when medical care is delayed until after the period of rapid childhood growth of the lung. Indeed, some patients may experience nearly complete clinical resolution of disease into adulthood. By the same token, children with chronic lung disease are especially vulnerable to the destructive consequences of episodic, inconsistent, and inadequate care. Thus, children with only moderate, but inadequately treated chronic lung disease remain at high risk to enter adulthood with significant chronic disability from lung dysfunction. Once lung growth has stopped, the potential for lung healing and resolution of lung dysfunction wanes. At present, it is not clear whether the rising mortality rate of patients with chronic obstructive pulmonary disease is due to alterations in environment, new etiologies or limitations in access to health care. What is apparent, however, is that approximately 23 percent of all children in this country under the age of 18 years are without comprehensive health insurance for all or part of the year, and of this group, nine percent have no health insurance coverage at all. It is clear, therefore, that access to health care for populations at risk for chronic lung disease must be examined carefully. The ultimate financial impact of poorly managed pediatric lung disease is increased expenditures for more costly forms of acute/intensive care later in life, the increase in physical disability, and the loss of productivity for a significant portion of the population. The immediate costs include frequent childhood hospitalizations, respiratory morbidity, school absence, family separation, and failure of the affected child to make the normal psychosocial adjustments to adolescence and adulthood.

Although the pathophysiology of chronic obstructive lung disease in children may remain incompletely understood, the outline for medical care of this clinical problem is generally well defined for the pediatric specialist who regularly evaluates and treats children with respiratory complaints. This approach involves comprehensive diagnostic evaluation of each patient with development of an individualized plan of management including: patient and family education; an individualized, rational program of medications/respiratory treatments; identification of specific "triggering" stimuli which lead to clinical decompensation; prevention of further lung injury (e.g., avoidance of "sidestream" smoke from cigarettes; avoidance of environmental inhalant toxins; annual influenza immunization/prophylaxis; rehabilitation of the patient and family into as normal a lifestyle as possible; comprehensive medical follow-up and attention to issues of general pediatric health care). Education of non-pediatric health care providers and school teachers to the symptoms and behaviors of children with respiratory disease is also necessary in order to heighten awareness of the problem of pediatric chronic obstructive pulmonary disease, in order to improve early identification and referral of these children to pediatric specialists and facilities offering comprehensive diagnostic and therapeutic programs for these children and their families.

Neonatal Respiratory Disorders

Lung disease is clearly the most common cause of mortality and morbidity in the newborn period. Respiratory disorders account for 20 percent of all infant deaths in the first year of life. The Respiratory Distress Syndrome (also called RDS or Hyaline Membrane Disease) has received much publicity and has been the focus of a continuing major research effort which has resulted in a 62 percent reduction in neonatal mortality from this disorder in the period from 1970-85. The price of this impressive reduction in mortality has been the appearance of a new lung disorder, Bronchopulmonary Dysplasia (BPD), a chronic lung disase of infancy and childhood which has evolved over the past 20 years since its original description into a major pediatric health problem. While BPD was first thought to be a unique sequella of RDS, it is now known that it occurs partially as a result of injury to the lung from the respiratory disorder and superimposed injury from the life sustaining oxygen therapy and assisted ventilation required by many infants with respiratory insufficiency in the newborn period. The more premature the infant the higher the likelihood that the infant will develop BPD if he/she experiences a respiratory disorder in the newborn period. Thus, a two pound baby with RDS may have a 50 percent risk of BPD while a full term newborn may have as little as a five percent risk of BPD when suffering from a neonatal respiratory disorder. There are at present in excess of 10,000 new cases of BPD yearly.

The large majority of BPD infants have an excellent long term prognosis. However, to achieve their potential for partial or complete resolution of the lung injury, extremely careful, thoughtful, and consistent care is required during their stay in the newborn intensive care unit, during the transition from hospital to home and during the first two years of life. Attention must be given to infant nutrition with diet carefully monitored to provide sufficient calories to assure optimal growth and weight gain. These infants frequently require 50 percent more calories than infants of equal birth weight but without lung disease. Almost 10 percent of BPD infants require home oxygen therapy and four percent will require oxygen therapy for at least three months after their discharge from the hospital. Bronchodilator and diuretic medications are frequently essential adjuncts to an effective therapeutic program. Parents require careful instruction in the home care treatment techniques. The patient's mother alone cannot provide 24 hour care for such an infant. Therefore, her spouse, significant other, sibling, grandparent, or friend must agree to assist and replace the mother on a regular respite basis for home care to succeed. In many cases where the infant has severe BPD with need for oxygen therapy, frequent monitoring of vital signs, and frequent medications, home nursing care is a key ingredient to the successful home care program. In the estimated 2,000 infants with chronic ventilator dependence from BPD and other pediatric respiratory disorders, home nursing for 8 to 24 hours daily is an absolute necessity to provide optimal care to these children.

Through the long term follow-up of these children we have learned that many of these infants and children who recover from BPD do so with a lasting, but most often very subtle lung injury. BPD children studied at 11 years of age, nine years after all clinical manifestations of BPD have disappeared, are found to have lower exercise tolerance than their peers, subtle abnormalities of small airway function, and after exercise, mild to moderate spasm of their airways (similar to children with reactive airways disease). The preventive medicine message is clear. Careful obstetric managment of the high risk pregnancy is important to prevent a significant portion of lung disease in the neonatal period and a chronic and more expensive form of lung disease in older children and adults. Secondly, children developing BPD or chronic lung disease in infancy must have access to comprehensive, long term health care provided by experts in pediatrics and respiratory disease to manage, control, and effectively limit, if possible, the long term impact of this respiratory sequela.

Need for New Initiatives

In a recent report to the Congress and the Secretary of Health and Human Services, the Task Force on Technology-Dependent Children proposed a comprehensive program for the community-based or foster care home of infants and children whose disorder falls in the severe end of the spectrum of respiratory illness. However, their definition of "a technology-dependent child as one from birth through the 21st year of age with a chronic disability, requiring the routine use of a medical device to compensate for the loss of a life-sustaining body function and who requires daily, ongoing care and/or monitoring by trained personnel" applies to many of the infants and children already discussed in this testimony. Their report is important in scope and their suggestions for action are both well reasoned and vitally appropriate. We believe that implementation of this report will lead to significant improvement in quality of life for these children and their families, while diminishing the need for frequent rehospitalizations. This may lead to an eventual substantial reduction in the costs of care for these children.

There are other initiatives that we endorse. These suggestions include:

o Pediatric Pulmonary Centers

Congress, in 1969, recognized the staggering impact of pediatric lung diseases and established the Pediatric Pulmonary Centers Program. The goal of the Centers was to increase the supply of trained pediatric lung specialists and allied health professionals trained in the treatment of pediatric respiratory conditions and to provide a regionalized network of care facilities providing a full spectrum of specialized services for children with the most serious lung disorders. Initially, 10 Centers were funded by the Regional Medical Program

Services. In 1973, when the RMPS was phased out, responsibility for the administration of the centers was transferred to the Bureau of Community Health Services, Office of Maternal and Child Health. In 1974, a long range plan proposed Pediatric Pulmonary Centers (PPC) be established in each of 22 designated regions of the country. This goal has never been achieved due to funding shortages.

Since 1982, the Centers have been funded from the Maternal and Child Health Services Block Grant which consolidated seven pre-existing categorical services into one grant. States were encouraged to develop their own programs to assure mothers and children access to quality maternal and child health services. Congress also recognized the continued need for programs of broader regional and national significance, providing that 10-15 percent of appropriated funds be retained for these purposes at the federal level, PPC's were classified as one such special program of regional and natioinal significance.

Presently, Centers are funded from a fixed percentage of the MCH block grant resulting in frequent delays in obtaining formal funding commitment leading to difficulty in retaining qualified personnel and mounting the desired level of program and service. In FY 88, there were eight centers funded with a total budget of $2.125 million. This commitment is far below the level required by the existing centers and deprives large areas of the country of the development of new centers.

To adequately mount and maintain an effective program of demonstration, education and clinical care in pediatric lung disorders, the pediatric pulmonary center programs should be strengthened and the number of centers expanded. The mandate of these centers might be expanded to include clinical research into new and effective measures to provide more of pediatric pulmonary care in the ambulatory setting and to answer some of the technological and therapeutic questions posing impediments to further efforts in home care of children with lung disease.

o Research Priorities

Until we have a better grasp of the mechanisms by which the lung develops and responds to environmental, toxic, infectious, and immunologic challenges, we will not be able to more effectively treat or prevent lung disorders of infancy and childhood, nor will we be able to prevent these disorders from leading to long term morbidity and disability when these childre reach adult years. Questions for which the definitive research solutions will take years include: Why are the lungs of the premature and even full term infant particularly vulnerable to respiratory illness? Why do these illnesses appear to result in life-long impairment of lung function? Why, in infant development is the lung capable of healing injury by resolution rather than scarring? How can the lungs host defenses against infection, immunologic challenges, oxygen toxicity and barotrauma, toxic inhalants be enhanced in the very young? We have in the past decade made giant strides in reducing the mortality from lung disease in infancy and childhood. In the next decade, the thrust of the research effort needs to be focused on the reduction in morbidity and suffering from pediatric lung diseases. This will require renewed dedication and the necessary funding to permit the needed basic and applied research and the completion of the development of a national network of Pediatric Pulmonary Centers to carry out the clinical, educational, and consultative efforts to assure achievement of this goal.

STATEMENT FOR FINANCE COMMITTEE HEARING ON CHRONICALLY ILL CHILDREN
SENATOR JOHN D. ROCKEFELLER IV

May 26, 1988

Mr. Chairman, thank you for having this hearing today. I admire the leadership and commitment to children you have shown in holding these very important hearings.

The past year's hearings on children's health issues have painted a bleak picture of how our children have been faring over the first half of this decade. It's unbelievable and unconscionable that so many of our children are not receiving even a minimum level of health care. Children with chronic illness are especially vulnerable.

The progress the medical profession had made in the medical treatment of children is astounding. Children with leukemia, diabetes, and cystic fibrosis, to name just a few chronic diseases, are living longer and better. Neonatal intensive care units are saving infants that less than five years ago would have had very slim chances of surviving.

But we are sorely lagging behind in one critical area. We lack a national policy on how to pay - not only for the medical technology and the constant care this technology requires - but for the lifetime needs of children with chronic conditions. The current system we have in place is confusing and hopelessly inadequate for those children who have multiple health problems.

The sickest children - those who require a respirator to breathe - are sometimes doomed to living in a hospital - instead of at home with their parents - because of the inflexibility of our current health insurance programs. Some changes have occurred. Through a special Medicaid waiver program, some technology-dependent children are able to live at home and receive needed health care services. But because of administrative, financial, and other barriers, access varies greatly between states. Even families with private insurance find that health benefits are quickly depleted if their child has special needs.

In West Virginia, the situation is particularly dire. Over 23 percent of West Virginian children live in families below the poverty line - and most of these children do not qualify for Medicaid. Only those families with yearly incomes less than $2,988 are eligible for medical assistance.

Yes, -- we are struggling with an enormous federal deficit. The burden of this deficit has been felt by every American - in some way or another. Our children have felt it acutely. Between 1979 and 1985, the number of children in poverty increased by 29 percent. While the number of children covered by Medicaid has dropped by 4 percent. It's time we quit classifying our children by their insurance status - the uninsurable, the underinsured, and the uninsured.

I don't need to recite one grim statistic after another. The witnesses - before us here today - can do a better job than I of documenting our pathetic health care financing system.

The time is at hand to shape a fair and comprehensive federal policy that guarantees every child access to health care. Thank you Mr. Chairman, for giving us this opportunity to learn more about a very important issue.

The successes the health care field has achieved should serve as a challenge to us. It's time we pursue a legislative agenda as aggressively as health care professionals have tackled the sometimes overwhelming medical needs of our children.

Children with special health care needs are not a drain on this nation's resources. They are our resources.

I am pleased today to welcome Dr. William Neal, Professor and Chairman of Pediatrics at West Virginia University School of Medicine. Dr. Neal cares for chronically ill children on a daily basis. He has been very active in drawing attention to and pushing for improvements in children's health issues in West Virginia and has been a valuable resource to me. I look forward to hearing his testimony today.

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These tables have been developed in order to provide an up-to-date picture of states' response to various federal Medicaid eligibility and maternity benefit options. This memorandum explains how to use each table.

A. **Characteristics of State Medicaid Programs for Children and Pregnant Women** (Table 1)

This fifty-state chart measures states' response to new Medicaid options, as well as their response to important, preexisting options for coverage of children and pregnant women. The following provides a more detailed explanation of each information column:

- **Maximum AFDC Payment, Family of 3:** Percentage of Federal Poverty: The first column shows the AFDC payment level for a family of three, which depicts the lowest Medicaid income eligibility test for most children in nearly all states, is shown in the first column.

- **All Financially Needy Children Under Eighteen:** The second column depicts state coverage of financially needy children under age 18. Since 1965 states have had the option of covering all financially needy children under age 18. A financially needy child is any child who qualifies for AFDC on the basis of income and resources but who is not "dependent" within the meaning of the AFDC program (that is, he or she does not live in a household in which one parent is dead, absent, incapacitated, or unemployed). These children also are known as "Ribicoff" children after the Senate sponsor of the 1965 amendment adding them as an optional coverage group. The classic Ribicoff child is one living in a two-parent working family, but other Ribicoff children include those living in institutions for the retarded, in foster care arrangements, or alone. As of 1987, sixteen of fifty-one jurisdictions still failed to cover all Ribicoff children under age 18.

- **Asterisked states:** Thirty-seven states and the District of Columbia show asterisks (*) in the second column. These asterisks depict those states that extend Medicaid coverage to medically needy individuals and families. (persons with incomes that are too high to qualify for cash assistance but too low to meet the cost of medically necessary care). States opting to cover the medically needy must at a minimum cover all pregnant women and children who would qualify for mandatory coverage were their incomes lower. These women and children (those whose family incomes exceed the AFDC payment level) can qualify for Medicaid by incurring large medical bills and thereby "spending down" to the medically needy eligibility level. Bear in mind that women and children whose incomes exceed the AFDC eligibility level but are below the OBRA '86 or '87 eligibility level (see discussion below) will no longer have to "spend down". Women and children whose incomes exceed the OBRA '86 or '87 eligibility levels, however, will have to spend down to the

- **Asset Test Waived:** Of the implementing jurisdictions, twenty-six (twenty-five states and the District of Columbia) have waived the asset test entirely. It is important to note that virtually all of the remaining states, while not waiving the asset test entirely, have broadened and simplified it considerably, eliminating from consideration such assets as homes, cars, and income-producing property. States that have not waived the asset test entirely are designated with a "No."

- **Continuous Eligibility for Pregnant Women:** Twenty-eight of the implementing jurisdictions (twenty-seven states and the District of Columbia) have guaranteed continuous eligibility for pregnant women. States that have not provided continuous eligibility for pregnant women are designated with a "No."

- **Presumptive Eligibility:** Sixteen states have implemented a presumptive eligibility program in all or part of the state.

Omnibus Budget Reconciliation Act of 1987 (OBRA '87): In December, 1987, Congress passed legislation (Pub. L. 100-203) which gave states the option of extending coverage of pregnant women and infants up to 185 percent of the federal poverty level.

- **Expanded Financial Coverage over 100 Percent:** As of May, 1988, nine states had enacted this option. Of these, West Virginia and Iowa had not opted to extend coverage all the way to 185 percent of the federal poverty level.

Highest Income Eligibility Levels: The last two columns of the chart show the highest Medicaid income eligibility levels for pregnant women, infants, and children as a percentage of the federal poverty level.

- **Pregnant Women and Infants: Percent of federal poverty:** the states' highest income eligibility level is shown. This level is the highest of eligiblity level among AFDC payment level, the medically needy income eligibility level, the OBRA '86 standard, or the OBRA '87 standard.

- **Children over 1: Percent of federal poverty:** In the 26 jurisdictions which have chosen to cover "OBRA '86" children over age one, the higher income standard for this subgroup of children is depicted parenthetically.

B. **Enriched Maternity Services** (Table 2)

The second table shows those states which, as of April 1988, have elected to expand the package of maternity services they will pay for. Fourteen states have chosen this option. Two cover the services by increasing the global fee paid. Three pay a separate monthly, all-inclusive fee for the enriched services. The remainder pay for each service on a per-encounter basis.

medically needy eligibility level (capped by federal law at 133 percent of the AFDC payment level).

Omnibus Budget Reconciliation Act of 1986 (OBRA '86): In 1986 Congress amended the Medicaid program to provide states considerable new flexibility to strengthen and expand coverage of pregnant women and children. These amendments, contained in the Omnibus Budget Reconciliation Act of 1986 (OBRA '86), permit states to:

- Cover women and infants with family incomes between the AFDC eligibility level and the federal poverty level;
- Phase in coverage of children ages one to five with family incomes between the AFDC eligibility level and the federal poverty level;
- Waive application of any asset test in the case of pregnant women and children younger than five;
- Provide continuous coverage to pregnant women, throughout their pregnancies and the sixty-day postpartum period, regardless of a change in income;
- Provide presumptive (i.e., immediate and temporary) eligibility to pregnant women during the period when their formal applications are considered.

- **Expanded Financial Coverage: Pregnant Women and Infants:** This column depicts states that have elected to take advantage of the OBRA '86 option to raise the income eligibility level above the AFDC level. A state is listed as a "yes" if it has not only enacted enabling legislation but also has a fixed effective date.

  A total of thirty-nine jurisdictions (thirty-eight states and the District of Columbia) have expanded income eligibility for pregnant women and infants. California's income eligibility levels already exceed those permitted under OBRA '86.

- **Expanded Financial Coverage: Children Over 1:** A total of twenty-six jurisdictions (twenty-five states and the District of Columbia) already have elected to continue coverage of "OBRA '86" children beyond age one. States have the option of either:(a) phasing in coverage of children on a year-by-year basis up to age 8; or (b), as of July, 1988, covering some or all children under age 5 immediately and phasing in coverage of 5-to-8 year olds. Other than making the threshold decision to extend coverage beyond age one, states appear not to have decided this issue conclusively as yet. Thus, you will need to check with your individual state to see where it has set the age cutoff for this new group of children.

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Presented by
Sara Rosenbaum

Mr. Chairman and Distinguished Members of this Committee:

The Children's Defense Fund (CDF) is pleased to have this opportunity to testify today regarding child health. CDF is a national public charity which engages in research and advocacy on behalf of the nation's low income and minority children. For fifteen years, CDF's health division has made extensive efforts to improve poor children's access to medically necessary care, including both primary and preventive services, as well as medical care requiring the most sophisticated and costly interventions currently available.

I. The Health Status of Children

Both ends of the medical care spectrum -- preventive and intensive -- are vital to the health and well-being of children. All children need primary care, including comprehensive maternity care prior to birth, ongoing health exams and followup treatment, care for self-limiting illnesses and impairments (such as influenza or strep throat), and vision, hearing, and dental care. Additionally about one in five children will be affected during childhood by at least one mild chronic impairment, such as asthma, a correctable vision or hearing problem, or a moderate emotional disturbance, which will require ongoing attention.

Beyond these basic health needs, a small percentage of children require more extensive and expensive medical care; and a modest proportion of this group will face truly extraordinary health care costs over their lifetimes. About four percent of all children (a figure which by 1979 was more than double the percentage reported in 1967)[1] suffer from one or more chronic impairments resulting in a significant loss of functioning. Included in this group are children suffering from degenerative illnesses, multiple handicaps, and major orthopedic impairments. About two percent of all children suffer from one of eleven major chronic childhood diseases, including cystic fibrosis, spina bifida, leukemia, juvenile diabetes, chronic kidney disease, muscular dystrophy, hemophilia, cleft palate, sickle cell anemia, asthma, and cancer.[2] Also included in this group are the several thousand children who are dependent on some form of life support system.

Additionally, nearly 7 percent of all infants are born at low birthweight (weighing less than 5.5 pounds) each year.[3] Virtually all will require extended medical services. About 43,000 low birthweight infants (approximately 18 percent of all such babies) weigh less than 3.3 pounds at birth and will require major medical care during the first year of life. About 9600 infants will incur first year medical costs alone that exceed $50,000, and a portion will require ongoing care throughout their lives.[4] Low birthweight infants are at three times the risk of developing such permanent impairments as autism, cerebral palsy and retardation.[5]

II. The Health Needs of Children

Most children, even children with impairments, require relatively modest levels of health care. Only about five percent of all children incur annual medical costs in excess of $5,000, and only about 5 percent of these -- .25 percent of all children -- have annual costs exceeding $50,000.[6] Both groups of children -- those with routine health care needs and those with high cost medical problems -- can and should be considered catastrophic cases, if (as is appropriate) the term "catastrophic" is defined in relation to family income. Moreover for a child with special health care needs, the most sophisticated care can and should be considered "primary", since early medical and health interventions can control, and even ameliorate, the effects of longterm illness and disability and promote the greatest possible growth and development in the least restrictive environment.

For more and more families, even basic child health needs can be "catastrophic" in size, if not in expectation. Between

1982 and 1985, the number of completely uninsured children climbed by 16 percent.[6a] In 1985, three quarters of the 11 million uninsured children,[7] and two-thirds of the more than 9 million uninsured pregnant women,[8] had family incomes below 200 percent of the federal poverty level.

Poor and near-poor uninsured families, when confronted with even normal child health expenditures of several hundred dollars per year, face insurmountable health care barriers. As a result, uninsured low income children receive 40 percent less physician care and half as much hospital care as their insured counterparts.[9]

The uninsured are disproportionately likely to be children. In 1985, children under 18 comprised 25 percent of the under-65 population, but one-third of the uninsured under-65 population.[10] Moreover, they are disproportionately likely to be poor. Over 60 percent of all uninsured persons in 1985 had family incomes below 200 percent of the federal poverty level, and one-third had family incomes below 100 percent of the federal poverty level.[11] Even a parent's access to employer insurance by no means assures relief for a child. In 1985, 20 percent of all uninsured children lived with a parent who had private coverage under an employer plan.[12]

The two main causes of children's lack of health insurance are the major gaps in the employer-based health insurance system and the failure of Medicaid, the nation's major public health insurance program for children, to compensate for the failings of private plans.

The Private Health Insurance System Is Leaving More American Children Uninsured

Our nation relies primarily on private health insurance to meet much of the health care costs of the working-age population and its dependents. Most of this private insurance is provided as an employment-related benefit. Employer-sponsored health care plans are the single most important source of private health care coverage for Americans younger than sixty-five. In 1984, over 80 percent of all privately insured American children were covered by employer plans.[13]

Yet during the 1980's, dependent coverage under employer-provided health insurance plans has undergone serious erosion. In 1982, employer plans covered over 47 million non-workers, including 36 million children. By 1985, even though there were actually more workers covered by employer plans than in 1982 (88 million versus 84 million), the number of covered children dropped to less than 35 million.[14] The recent decline in employer-provided coverage has been most apparent among children for several reasons. First, in pursuing cost containment strategies, employers have frequently reduced or eliminated their premium contributions for family coverage.[15] As a result, lower income employees faced with dramatic cost increases have been forced to drop family coverage.

Second, the employer insurance system also completely excludes millions families at the lower end of the wage scale -- the fastest growing part of the job sector. Thirty percent of all employers who pay the minimum wage to more than half their work force offer no health insurance.[16] As these young adult workers have families, the children are affected by their parents' lack of coverage.

Third, as the number of single parent households grows, the percentage of insured children declines. Because single parent households have only one wage earner, the probability that a child will have access to an employer plan decreases. In 1984, children in single-parent households were about 3 times more likely than those in two parent households to be completely uninsured.[17] Thus, the employer-sponsored health insurance system excludes those children whose parents' employers either do

TABLE I. CHILDREN COVERED BY EMPLOYER OR UNION PROVIDED GROUP HEALTH INSURANCE PLANS, 1980 AND 1985

	1980				1985			
	Under 3	AGE 3-5	AGE 6-14	TOTAL 0-14	Under 3	AGE 3-5	AGE 6-14	TOTAL 0-14
ALL CHILDREN AGES 0-14	10,339	9,514	31,167	51,020	10,857	10,815	30,194	51,866
ALL POOR* CHILDREN AGES 0-14	2,118	1,919	5,567	9,604	2,441	2,448	6,037	10,926
CHILDREN 0-14 COVERED BY EMPLOYER OR UNION PROVIDED GROUP PLANS (number)	6,564	6,201	20,336	33,101	6,280	6,421	18,619	31,320
(as a percent of all children)	63.5%	65.2%	65.2%	64.9%	57.8%	59.4%	61.7%	60.4%
POOR CHILDREN 0-14 COVERED BY EMPLOYER OR UNION PROVIDED GROUP PLANS (number)	389	315	936	1,640	292	326	786	1,404
(as a percent of all poor children)	18.4%	16.4%	16.8%	17.1%	12.0%	13.3%	13.0%	12.9%
PERCENT OF ALL CHILDREN WHO ARE POOR	20.5%	20.2%	17.9%	18.8%	22.5%	22.6%	20.0%	21.1%
PERCENT OF COVERED CHILDREN WHO ARE POOR	5.9%	5.1%	4.6%	5.0%	4.6%	5.1%	4.2%	4.5%

* Poor equals family income of less than 100 percent of the federally defined poverty level.

not offer any family coverage or else offer it only at an unaffordable cost. As a result of these trends, a child living in a poor working family is only about half as likely as a non-poor child to have private insurance.[18]

I would like to present today some preliminary results from a forthcoming CDF study, to be issued in the late fall, on children's changing relationship to the public and private health insurance system. Our preliminary findings on low income children's private health insurance coverage, which are based analysis of multi-year data from the Bureau of Census, are particularly disturbing.

This preliminary analysis examines public and private health insurance coverage among children under age 14 for the years 1980 and 1985. Table I shows that in 1980, 33.1 million children (approximately 65 percent of all children under age 14) had employer or union provided coverage. Only 17 percent of all poor children in this age group, 1.6 million out of 9.6 million, had such coverage, however. Thus, while poor children under 14 comprised 18.8 percent of all children in 1980, they constitute only 5.0 percent of all employer insured children.

By 1985, only 60.4 percent of a much larger group of children, and only 12.9 percent of all poor children under age 14, had private coverage. This represents a drop of 6.9 percent for all children and a breathtaking 24.7 percent for all poor children. Coverage among poor children fell precipitiously among all 3 age cluster shown in Table I, but by an astounding 34.9 percent among poor children under age 3.

Table II illustrates the changing nature of employer contribution patterns. In 1980 40.0 percent of all children, but only 28.3 percent of all poor children, were covered by plans in which an employer or union paid the full cost of coverage. By 1985 the proportion of fully subsidized children had declined by 8.8 percent, to 36.5 percent. While the percentage of fully financed poor children constant, there were 62 thousand fewer such children. We believe that a primary cause of the disappearanced of these children was the loss of jobs in the early 1980s that carry with them fully subsidized health insurance. Changing demographics among white women may also be a significant factor, with a notable increase in the early 1980s in unmarried childbearing among young white women who are less likely to be employed at firms that fully subsidize their employees, family coverage.

At the same time there were dramatic drops in the number of covered poor children whose parents' employers or unions paid no portion of the cost of coverage. These children simply disappeared from the system. Since there was no concommitant significant increase in the percentage of partly or fully subsidized children, we presume that these children's disappearanceresulted from their, parents inability to any longer afford the cost of coverage. Data from the National Center for Health Services Research indicate that nearly 90 percent of persons with access to employer coverage but without coverage

TABLE II. CONTRIBUTIONS OF EMPLOYER OR UNION TO HEALTH INSURANCE PLAN COSTS, FOR COVERED CHILDREN IN HOUSEHOLDS, AGES 0-14, U.S., 1980 AND 1985
(numbers in thousands)

		1980				1985			
		UNDER AGE 3	AGE 3-5	AGE 6-14	TOTAL 0-14	UNDER AGE 3	AGE 3-5	AGE 6-14	TOTAL 0-14
TOTAL COVERED CHILDREN	(number)	6,564	6,201	20,336	33,101	6,280	6,431	18,619	31,330
TOTAL COVERED POOR[a] CHILDREN	(number)	389	315	936	1,640	292	326	786	1,404
PERCENT OF ALL COVERED CHILDREN WHO ARE POOR		5.9%	5.1%	4.6%	5.0%	4.6%	5.1%	4.2%	4.5%
COVERED CHILDREN WITH ALL COSTS PAID BY EMPLOYER OR UNION	(number)	2,624	2,399	8,218	13,241	2,280	2,350	6,802	11,432
	(percent)	40.0%	38.7%	40.4%	40.0%	36.3%	36.5%	36.5%	36.5%
COVERED POOR CHILDREN WITH ALL COSTS PAID BY EMPLOYER OR UNION	(number)	105	90	269	464	78	94	230	402
	(percent)	27.0%	28.6%	28.7%	28.3%	26.7%	28.8%	29.3%	28.6%
PERCENT OF COVERED CHILDREN WITH ALL COSTS PAID WHO ARE POOR		4.0%	3.8%	3.3%	3.5%	3.4%	4.0%	3.4%	3.5%
COVERED CHILDREN WITH SOME COSTS PAID BY EMPLOYER OR UNION	(number)	3,558	3,433	10,992	17,983	3,686	3,732	10,940	18,358
	(percent)	54.2%	55.4%	54.1%	54.3%	58.7%	58.0%	58.8%	58.6%
COVERED POOR CHILDREN WITH SOME COSTS PAID BY EMPLOYER OR UNION	(number)	224	170	552	946	191	205	470	866
	(percent)	57.6%	54.0%	59.0%	57.7%	65.4%	62.9%	59.8%	61.7%
PERCENT WITH SOME COST PAID WHO ARE POOR		6.3%	5.0%	5.0%	5.3%	5.2%	5.5%	4.3%	4.7%
COVERED CHILDREN WITH NO COST PAID BY EMPLOYER OR UNION	(number)	382	368	1,127	1,877	314	349	877	1,540
	(percent)	5.8%	5.9%	5.5%	5.7%	5.0%	5.4%	4.7%	4.9%
COVERED POOR CHILDREN WITH NO COST PAID BY EMPLOYER OR UNION	(number)	60	55	115	230	23	27	86	136
	(percent)	15.4%	17.5%	12.3%	14.0%	7.9%	8.3%	10.9%	9.7%
PERCENT OF COVERED CHILDREN WITH NO COST PAID BY EMPLOYER OR UNION WHO ARE POOR		15.7%	14.9%	10.2%	12.3%	7.3%	7.7%	9.8%	8.8%

[a] Poor equals family income of less than 100 percent of the federally defined poverty level.

have none because they cannot afford the cost of their plans.

Medicaid, the Major Public Insurance Program for Families with Children, Is Covering Fewer Children

Medicaid, enacted in 1965, is the nation's largest public health financing program for families with children. Unlike Medicare, which provides almost universal coverage of the elderly without regard to income, Medicaid is not a program of universal or broad coverage. Because Medicaid is fundamentally an extension of America's patchwork of welfare programs, it makes coverage available primarily to families that receive welfare. With a few exceptions (including pregnant women and young children) nonelderly individuals and families that do not receive either AFDC or Supplemental Security Income (SSI) are categorically excluded. For example, a family consisting of a full-time working father, mother, and two children normally is excluded from Medicaid, even if the father is working at a minimum wage job with no health insurance and the family's income is well below the federal poverty line. Moreover, even though states have had the option since 1965 to cover all children living below state poverty levels regardless of family structure, 16 states still fail to do so.[19] Table III.

In addition to its use of restrictive eligibility categories, Medicaid excludes millions of poor families because its financial eligibility standards for most families are tied to those used under the AFDC program. In more than half the states, a woman with two children who earns the minimum wage (about two-thirds of the federal poverty level for a family of three in 1986) would find that she and her children are ineligible for coverage.[20] In 1986, despite very deep poverty and federal and state improvements, only 53.0 percent of all poor children under 3 had Medicaid. Table IV shows that while the number of poor children under 14 with Medicaid grew by 20.6 percent between 1980 and 1985. However, the number of poor children under age 14 grew during these years by 13.8 percent. Thus, real Medicaid growth was relatively modest (and in the case of children ages 6-14, nearly wiped out by their poverty increase) during a period when private coverage rates among poor children fell by 25 percent.

As a result of improvements enacted by Congress in 1984 and 1986, 1987 and in 1988, many previously uninsured low-income pregnant women and children will be aided.

- The Deficit Reduction Act of 1984 (DFRA) mandated that states provide Medicaid coverage to all children younger than five with family incomes and resources below AFDC eligibility levels.
- The Deficit Reduction Act and the Consolidated Omnibus Budget Reconciliation Act of 1986 (COBRA) together mandate coverage of all pregnant women with income and resources below state AFDC eligibility levels.
- The Omnibus Budget Reconciliation Act of 1986 (OBRA `86) permits states at their option to extend automatic Medicaid coverage to pregnant women and children under age five with incomes less than the federal poverty level but in excess of state AFDC eligibility levels. Table III indicates that by May, 1988, all but 11 jurisdictions adopted OBRA `86 coverage. When fully implemented in every state, the OBRA `86 amendments could reduce by 36 to 40 percent the number of uninsured pregnant women and young children nationwide.[21]

Children's Defense Fund

Table III

Characteristics of State Medicaid Programs for Children and Pregnant Women, May 1988

			Omnibus Budget Reconciliation Act of 1986					OBRA '87	Highest Income Eligibility:		
State	Max. AFDC Payment, Family of 3: % of of Federal Poverty[1]	All Financially Needy Children Under 18[1]	Expanded Financial Coverage: Pregnant Women and Infants	Expanded Financial Coverage: Children Over 1	Asset Test Waived	Continuous Eligbility for Pregnant Women	Presumptive Eligibility	Expanded Financial Coverage 100%	Preg. Women & Infants: % of Federal Poverty	Children Over 1: % of Fed. Poverty[4]	ST
Alabama	15.4	No	Yes	No	Yes	Yes	Yes	No	100	15.4 (100)	AL
Alaska	77.4	Yes	No	No	No	No	No	No	77.4	77.4	AK
Arizona	37.8	Yes*	Yes	Yes	Yes	Yes	No	No	100	51.7 (100)	AZ
Arkansas	24.8	Yes*	Yes	Yes	No	Yes	Yes	No	100	33.3 (100)	AR
California	79.6	Yes*	NA	NA	No	No	No	No	106.5	106.5	CA
Colorado	44.6	No	No	No	No	No	No	No	54.3	54.3	CO
Connecticut	65.2	Yes*	Yes	No	Yes	Yes	No	No	100	91.4	CT
Delaware	40.0	Yes	Yes	No	Yes	Yes	No	No	100	40.0	DE
District of Columbia	47.0	Yes*	Yes	Yes	Yes	Yes	No	No	100	62.6 (100)	DC
Florida	34.1	Yes*	Yes	Yes	Yes	Yes	Yes	No	100	46.3 (100)	FL
Georgia	33.0	Yes*	Yes	Yes	Yes	3	No	No	100	44.1 (100)	GA
Hawaii	52.5	No*	No	No	No	No	No	No	53.5	53.3	HI
Idaho	39.2	No	Yes	No	No	No	No	No	68	39.2	ID
Illinois	44.1	Yes*	Yes	3	Yes	3	3	No	100	59.1	IL
Indiana	33.0	No	Yes	No	Yes	Yes	Yes	No	50	33.0	IN
Iowa	49.2	Yes*	Yes	Yes	No	No	No	Yes	150	65.5 (100)	IA
Kansas	46.7	Yes*	No	No	No	No	No	No	59.4	59.4	KS
Kentucky	25.4	No*	Yes	Yes	No	No	No	No	100	34.5 (100)	KY
Louisiana	24.5	No*	No	No	No	No	No	No	33.3	33.3	LA
Maine	52.3	Yes*	Yes	Yes	Yes	Yes	No	Yes	185	72.0 (100)	ME
Maryland	44.5	Yes*	Yes	No	Yes	Yes	Yes	No	100	52.8	MD
Massachusetts	63.4	Yes*	Yes	Yes	Yes	Yes	Yes	Yes	185	84.9 (100)	MA
Michigan	80.4	Yes*	Yes	Yes	Yes	Yes	No	Yes	185	69.6 (100)	MI
Minnesota	68.6	Yes*	Yes	Yes	Yes	Yes	No	Yes	185	91.5 (100)	MN
Mississippi	15.5	Yes	Yes	Yes	No	Yes	No	Yes	185	47.4 (100)	MS
Missouri	36.0	Yes	Yes	Yes	No	No	No	No	100	36.0 (100)	MO
Montana	45.7	Yes*	No	No	No	No	No	No	52.1	52.1	MT
Nebraska	45.2	Yes*	Yes	Yes	Yes	Yes	Yes	No	100	58.1 (100)	NB
Nevada	36.8	No	No	No	No	No	No	No	36.8	36.8	NV
New Hampshire	51.2	No*	No	No	No	No	No	No	60.3	60.3	NH
New Jersey	52.1	Yes*	Yes	Yes	Yes	Yes	Yes	No	100	69.9 (100)	NJ
New Mexico	33.3	No	Yes	Yes	No	No	Yes	No	100	33.3 (100)	NM
New York	64.1	Yes*	No	No	No	No	Yes	No	79.6	79.6	NY
North Carolina	33.4	Yes*	Yes	Yes	Yes	Yes	Yes	No	100	45.2 (100)	NC
North Dakota	58.6	No*	No	No	No	No	No	No	56.1	58.6	ND
Ohio	39.0	Yes	Yes	No	No	Yes	No	No	100	39.0	OH
Oklahoma	40.0	Yes*	Yes	Yes	Yes	Yes	No	No	100	40.0 (100)	OK
Oregon	51.2	Yes*	Yes	Yes	Yes	Yes	No	No	100	68.3 (100)	OR
Pennsylvania	47.1	Yes*	Yes	Yes	Yes	No	Yes	No	100	54.8 (100)	PA
Rhode Island	64.9	Yes*	Yes	Yes	Yes	Yes	No	Yes	185	81.7 (100)	RI
South Carolina	25.7	Yes	Yes	No	Yes	Yes	No	No	100	56.8	SC
South Dakota	31.7	No	Yes	No	Yes	Yes	No	No	100	31.7	SD
Tennessee	20.0	Yes*	Yes	Yes	No	Yes	Yes	No	100	45.5 (100)	TN
Texas	23.7	Yes*	No	No	No	No	No	No	31.6	31.6	TX
Utah	48.5	Yes*	Yes	Yes	Yes	Yes	Yes	No	100	89.4 (100)	UT

Vermont	70.7	Yes*	Yes	Yes	No	Yes	No	Yes	185	78.5 (100)	VT
Virginia	37.5	No*	Yes	No	Yes	No	No	No	100	100	VA
Washington	63.5	No*	Yes	Yes	No	Yes	No	No	90	71.6 (90)	WA
West Virginia	32.1	No*	Yes₂	Yes	Yes	Yes	No	Yes	150	37.4 (100)	WV
Wisconsin	60.1	Yes*	Yes	No	No	No	Yes	No	100	83.5	WI
Wyoming	46.5	No	Yes	No	No	No	No	No	100	46.5	WY
			39	26	26	28	16	9			

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* = State has a medically needy program.
1. Current as of November 1987.
2. 100% state funded.
3. State undecided.
4. Parenthetical figures represent income eligibility levels for low income children up to age eight. Actual age limit is set by the state.

TABLE 2

ENRICHED MATERNITY SERVICES, APRIL 1988

	RISK ASSESS.	CASE MANAGE.	OUT-REACH	COUN-SELING	NUTRI-TION	HOME VISITING	HEALTH ED.	CHILDBRTH ED.	METHOD OF REIMBURSEMENT		
									INCREASED GLOBAL	PER ENCOUNTER	PREPAID MONTHLY FEE
ARKANSAS	x	x		x	x	x	x	x		x	
CALIFORNIA	x			x	x		x	x		x	
DELAWARE (1)	x	x	x	x	x	x	x	x			x
KANSAS	x	x	x	x	x	x	x	x		x	x
MASSACHUSETTS	x	x	x	x	x	x	x	x	x		
MICHIGAN	x	x	x	x	x	x	x	x		x	
MINNESOTA (2)	x	x		x	x	x	x	x		x	
MISSOURI (1)	x	x	x	x	x	x	x	x			x
NEW JERSEY	x	x	x	x	x	x	x	x	x		
NORTH CAROLINA	x	x	x	x	x	x	x	x		x	
OHIO	x	x	x	x	x	x	x	x		x	
OREGON	x	x			x					x	
SOUTH CAROLINA	x	x	x	x	x	x	x			x	
UTAH	x	x	x	x	x	x	x	x		x	
VIRGINIA (2)	x	x			x	x	x	x		x	

(1) Plan still waiting for final approval.

(2) Will be implemented as of July 1, 1988.

SOURCE: CHILDREN'S DEFENSE FUND

TABLE IV. ALL CHILDREN UNDER AGE 14 IN HOUSEHOLDS AND ALL CHILDREN UNDER AGE 14 WITH MEDICAID COVERAGE, U.S., 1980 AND 1985

(numbers in thousands)

	1980				1985				CHANGE 1980-1985			
	UNDER AGE 3	AGE 3-5	AGE 6-14	TOTAL 0-14	UNDER AGE 3	AGE 3-5	AGE 6-14	TOTAL 0-14	UNDER AGE 3	AGE 3-5	AGE 6-14	TOTAL 0-14
ALL CHILDREN	10339	9549	31167	51055	10857	10815	30194	51866	518	1,266	(973)	811
ALL POOR[a] CHILDREN (number)	2118	1919	5567	9604	2441	2448	6037	10926	323	529	470	1,322
(as a percent of all children)	20.5%	20.1%	17.9%	18.8%	22.5%	22.6%	20.0%	21.1%	15.3%	27.6%	8.4%	13.8%
CHILDREN WITH MEDICAID (number)	1407	1366	3800	6573	1738	1655	3820	7213	331	289	20	640
(as a percent of all children)	13.6%	14.3%	12.2%	12.9%	16.0%	15.3%	12.7%	13.9%	23.5%	21.2%	0.5%	9.7%
POOR CHILDREN WITH MEDICAID (number)	995	971	2706	4672	1301	1309	3024	5634	306	338	318	962
(as a percent of all children with Medicaid)	70.7%	71.1%	71.2%	71.1%	74.9%	79.1%	79.2%	78.1%	30.8%	34.8%	11.8%	20.6%
(as a percent of all poor children)	47.0%	50.6%	48.6%	48.6%	53.3%	53.5%	50.1%	51.6%				

- The Omnibus Budget Reconciliation Act of 1987 (OBRA '87) permits states to extend coverage of women and infants up to 185 percent of the federal poverty level (one third of all uninsured women of childbearing age have family incomes between 100 and 200 percent of the federal poverty level), and permits coverage of children up to age 8 with family incomes below the federal poverty level. As of May, 1988, 9 states had taken advantage of this option.

However, even if fully implemented, these new laws obviously will not compensate for Medicaid's shortcomings as a source of third party coverage for uninsured children. The reforms do not affect children over age 8 with family incomes below the federal poverty level. Moreover, these reforms provide no relief for the millions of uninsured, nonpregnant, poor parents, whether working or unemployed.

The Special Needs of Children with High Cost Health Problems

By expanding the number of children with health insurance, Congress would also provide relief for some of the uninsured children with high cost medical needs which arise as a result of serious illness or disability. Medical problems disproportionately affect low income children who are more likely than their nonpoor counterparts to be born at low birthweight and who suffer more frequent, and more severe, illnesses and disabilities.[23] Thus, insuring more low income children would also assist many chronically ill and disabled children. Among the 5 percent of the 1.2 million children who have an illness or disability sufficiently serious to limit normal childhood activities, (five percent of all children) we estimate that about 400,000 are poor and near-poor (i.e., incomes below 200% of the federal poverty level) and completely uninsured.

However, meeting the health needs of even insured children with disabilities can require a depth and scope of coverage that is beyond both normal Medicaid or private insurance plans. Many plans, for example, are inadequate to cover the 19,000 such children (9600 of whom are under one year of age) who annually incur more than fifty thousand dollars in health care costs.

The traditional notion of health insurance is that it provides protection against grave health costs. But over time the nation has developed public and private health insurance systems that are designed to meet normative, rather than high cost, medical care needs. Both public and private health insurers have developed myriad ways to limit their exposure for high-cost illnesses and disabilities, in favor of providing subsidies for more routine health expenditures:

- Among employers responding to a major health insurance survey conducted in 1986, 73 percent indicated that their plans exclude coverage of preexisting conditions.[24] More plans now also contain riders that exclude coverage of certain conditions that may develop among enrollees, such as cancer.
- Only about 75 percent of plans offered by medium and large-sized firms between 1980 and 1985 contained protections against huge out-of-pocket costs borne by enrollees in the event of catastrophic illness.[25]
- Only 67 percent of mid-and-large-sized firms offered extended care benefits between 1980 and 1985, and only 56 percent offered home health benefits.[26]
- In 1977 only 8.3 percent of all children had unlimited private coverage for major medical benefits, and one-third had coverage for a quarter million dollars of care or less.[27]
- Fourteen state Medicaid programs place absolute limits on the number of inpatient hospital days they will cover each year, with some states limiting coverage to as few as 12-15 days per year.[28] About an equal number place similar limits on coverage of physicians' services. Others place strict limitations on such vital services as prescribed drugs and diagnostic services.
- Finally, Medicaid, like private health insurance frequently fails to cover extended home health and related services (including such non-traditional items as home adaptation). When such coverage is available, it may be provided only on a case-by-case exception basis.

The question of whether private and public insurers should provide comprehensive but shallow, versus deep but limited, coverage is a complex one, particularly since so many American families need a financial subsidy to meet even basic health costs. While this issue is being resolved however, thousands of uninsured are inadequately insured children with chronic health problems face serious underservice, particularly if they are low income.

Recommendations

We make two major sets of recommendations. Additionally we urge that, in constructing remedial legislation, the Committee not bifurcate children into "well" children and "sick" children. Unfortunately, children are not born with signs that tell their parents whether they will be healthy or injured in a car accident or develop cancer at age 9. It is essential that all remedies be built on a base of uniform eligibility and benefit standards for all children, so that supplemental programs for high risk children add scope and depth to a uniform plan rather than creating new eligibility groups.

INSURANCE REFORMS

Like the elderly 20 years ago, children are in great need of a uniform basic health coverage system. That system should contain the following elements:

- It should be available on the basis of an income-related to any family that needs maternity or pediatric coverage
- It should contain a uniform set of benefits, ranging from routine preventive services to intensive medical and remedial care, as well as health-related "hybrid" benefits such as coverage of early intervention services.
- It should contain provisions to aid and encourage enrollment into private plans, where available, by underwriting the cost of the premium for private coverage as part of the family's annual payment. Public benefits would then fill in gaps left by the employer plan.
- Eligibility should be significantly simplified. For example, a simple monthly income test should be utilized, under which the family's income is compared to the federal poverty level.
- Enrollment should be available through the workplace and local social security offices as well as local public aid agencies, and applications should be readily accessible.
- Eligibility redeterminations should be reduced to a simple semi-annual income statement.
- Reimbursement rates need to be competitive, and coverage must be direct, as is the case under Medicaid currently, since the families most in need of such a plan do not have the cash to lay out for services and be indemnified later.

We believe that the Medicaid reforms which have occurred in recent years are consistent with these recommendations, and that the time has come to permit the acute care portion of Medicaid to evolve into a basic coverage plan for families with children. Eligibility has been expanded and dramatically simplified. For pregnant women, the site of application has been moved through the presumptive eligibility program (which 15 states are now implementing). Benefits have been broadened. The excellent transitional Medicaid program recently designed by this Committee, the Bradley/Chafee/ Waxman maternity bill passed in December, and Senator Chafee's Med America proposal break additional ground in establishing an income-related fee system for near-poor families, which would replace the antiquated and impractical medically needy system. The transitional Medicaid program also makes a public subsidy available for the first time to meet the cost of employer-provided family coverage.

These significant reforms, taken together, have made possible a new way of thinking about Medicaid for families with children. It is now time to introduce uniform coverage and provider reimbursement methods, as well as uniform eligibility rules. It is also time to think about creative financing mechanisms, that would make these reforms possible. While we have made notable progress in recent years, it is also evident that the rate of erosion in coverage is outpacing us and that a more sizeable leap forward is essential.

In doing the research for our forthcoming book we have had occasion to re-read portions of the original Medicare debate. Many of the themes 20 years ago that led to enactment of that program -- deep poverty among the elderly and their dislocation from the employer coverage system -- are directly applicable to children today. As Senator Moynihan and others have pointed out, children today are the elderly of 20 years ago -- the poorest members of society. The insurance trends described here obviously are not some flash in the pan. They are longterm and we cannot afford delay enactment of a sizeable set of reforms, given the growing nature of the problem and the consequences of the lack of health insurance on children's access to care.

SYSTEM REFORMS

By 1990, given recent expansions, and assuming that current poverty rates hold, one in every five American infants and young children will be eligible for Medicaid, up from one in eight at the beginning of the decade. Many of the Medicaid reforms identified above would make it a stronger and better program for children. However financing alone is not enough. Thousands of communities still lack enough, or appropriate providers.

While insurance expansion and reform will probably remove many of the access barriers that now exist, there will be an ongoing need to plan and develop a range of primary and specialized programs.

Direct services will have to continue in underserved areas. The range of health, nutritional, medical and education programs frequently aimed at the same population of children will need to be monitored and evaluated. And the ongoing health status of children will have to be measured.

We think that these are all appropriate roles for state maternal and child health agencies. Therefore, we make the following recommendations:

- As proposed in Senator Chafee's Title V reform measure last year, agencies should cease limiting their work to certain categories of children with special needs. All children in a state, particularly lower income children who depend on publicly financed care, should fall within the mission of Title V agencies. We should no longer have cases in which children with cancer, or sickle cell anemia, or other health problems are told that their case is not within agency purview.
- State efforts to identify unmet need for maternal and child health services through an annual plan developed by Title V agencies should be further promoted and expanded. A national report on state Title V related activities and unment need should be prepared by the Secretary of Health and Human Services, as well.

- Initiatives designed to promote primary care activities should be supported. Basic routine and preventive health care for children over age one is essential. The basic health care needs of children should not be overlooked in favor of highly-technical care for children with special health care needs or highly-popular infant mortality prevention efforts. A balance between these activities is essential.

- States' Title V programs must be adequately funded to allow states to meet the programs dual service mission -- primary care for pregnant women and children, along with appropriate and necessary care for children with special health needs.

FOOTNOTES

1. Newacheck, P. W., Budetti P. P. & Halfon, "Trends in Activity Limiting Chronic Conditions Among Children," 76 AJPH 178 (Feb., 1986).

2. Butler, John, et. al., "Health Care Expenditures for Children with Chronic Illnesses" Issues in the Care of Children with Chronic Illnesses.

3. Hughes, D. et al, The Health of America's Children (Children's Defense Fund, Washington, DC, 1987).

4. Institute of Medicine, Preventing Low Birthweight (National Academy Press, 1986).

5. Healthy People: The Surgeon General's Report on Health Promotion & Disease Prevention (DHHS, Washington DC, 1978).

6. American Academy of Pediatrics, Health Care Financing Newsletter (1986).

6a. Chollet, Deborah, "The Erosion of Health Insurance Among the Non-Elderly Population: Public Policy issues and Options" (EBRI, Washington, D.C., 1987).

7. Sulvetta, Margaret and Swartz, Katherine, Chartbook of the Uninsured (Urban Institute, 1986).

8. Gold, Rachel and Kenney, Asta, "Paying For Maternity Care," 17 Fam Plann Perspect 107 (May-June, 1985).

9. Blendon, Robert, et. al., "Uncompensated Care by Hospitals or Public Insurance for the Poor: Does It Make a Difference?" 314 NEJM, 1160 May 1, 1986.

10. Chollet, op. cit.

11. Ibid.

12. Ibid.

13. Rosenbaum, S., "Children & Private Health Insurance," Recent Developments in the Financing & Organization of Health Care: Implications for Children. (Harvard University, in press).

14. Chollet, *op. cit.*

15. Ibid.

16. *A Children's Defense Budget*, (Washington, D.C., 1987).

17. Sulvetta, *op. cit.*

18. Rosenbaum, *op. cit.*

19. Hill, I., Unpublished survey, (National Governors Association, December, 1986).

20. A Children's Defense Budget, *op. cit.*

20a. Robert Wood Johnson Foundation, 1986.

21. Robert Wood Johnson Foundation, *Health Care for the Uninsured Program*, 1986.

21a. Estimates by the Children's Defense Fund.

22. Hughes et. al., *op. cit.*

23. Starfield, Barbara, "Ill Health and Social Status" *Milbank Quarterly*, 1985.

24. Rosenbaum, *op. cit.*

25. *Ibid.*

26. *Ibid.*

27. Ibid.

28. National Association of Children's Hospitals and Related Institutions, Unpublished data, (Alexandria, VA, March, 1987).

STATEMENT OF
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It is a pleasure to be here today to discuss the Institute's work on the financing of maternity care and to address briefly the relationship between family planning and infant health. We applaud this committee's interest in meeting the health needs of children -- needs long neglected at high human and financial cost.

For our children to be born healthy and thrive in their infancy years, two preliminary conditions must be met: they must arrive in the world when their parents, particularly the mother, are best able to care for them, and they must be born as healthy and free of handicapping conditions as possible. This means that both family planning services and early, regular prenatal care during pregnancy and childbirth must be available and actually used.

In 1985, we decided to examine how maternity care is financed in the United States and to document any problems we identified. We focused on financing issues because they can be relatively easily rectified through appropriate policies and programs, whereas efforts to motivate individual women to seek care would be far more complicated. Over a two-year period, the institute analyzed most major national data tapes containing information about maternity services and payment for services and conducted seven original surveys. The results of this research are reported in Blessed Events and the Bottom Line: Financing Maternity Care in the United States and in a lengthy volume of background reports.

The study demonstrates how our current system of financing maternity care militates against many women who are covered neither by Medicaid nor private insurance -- they often get care late in pregnancy or not at all, get care inconsistently from different sources and deliver their babies in facilities where they arrive without medical records. Congress in recent years has tried to alleviate this situation, and we hope this Committee may be instrumental in bringing about further improvements this year.

FAMILY PLANNING, PRENATAL CARE AND INFANT HEALTH

There is a considerable body of evidence linking family planning and maternal and child health.

- In 1981, the congressionally-mandated Select Panel for the Promotion of Child Health reported that "A voluminous body of research indicates...infant mortality, low birthweight and stillbirths can be reduced through family planning."
- A 1981 study found that increased use of family planning services by low income women between 1964 and 1977 was the largest factor (after the legalization of abortion) contributing to declining neonatal mortality.
- The Institute of Medicine's 1985 report, Preventing Low Birthweight, concluded that "family planning services should be an integral part of overall strategies to reduce the incidence of low birthweight in infants."

The relationship between prenatal care and the reduction of infant mortality and other adverse birth outcomes has also been abundantly documented, most recently by the Institute of Medicine in its report, Preventing Low Birthweight. Our own work buttresses that body of research:

- The infant mortality rate is 9.7 per 1,000 live births among newborns whose mothers began prenatal care in the fist trimester; it rises to 12.5 per 1,000 when care was initiated later in pregnancy; and it jumps to 48.7 per 1,000 when the mother obtained no prenatal care at all.
- Women who obtain insufficient prenatal care are twice as likely as those who have sufficient care to have a low birthweight baby (10 percent versus 5 percent);
- Women with insufficient care are also more likely to have their baby prematurely (13 percent versus eight percent).

The evidence clearly indicates that women who have difficulty in paying for health care also obtain inadequate prenatal care. Fully a third of pregnant women get insufficient prenatal care and the groups of women most likely to be uninsured -- the poor, minorities, the unemployed and unmarried women -- are also those most likely to have obtained inadequate or no care. The proportion of uninsured women who obtain only late prenatal care is twice the national average, and the proportion who obtain no care is about four times the national average. A recent report by the General Accounting Office, based on interviews with over a thousand new mothers, found that nearly two-thirds of Medicaid recipients and uninsured women had received insufficient prenatal care. Lack of financial resources was the reason most often cited.

THE COST OF HAVING A BABY

Having a baby is a costly proposition. The average bill in 1985 was $4,300. Even an uncomplicated pregnancy cost about $2,900 -- with 60 percent going for the hospital -- and, of course, the cost goes up as complications occur, so that the bill can run to many thousands of dollars if an infant needs neonatal intensive care.

These costs are particularly devastating when it is kept in mind that most births are to couples who are young and often employed in entry-level positions, many without health insurance benefits. Almost half of all births are to women with incomes below 200 percent of poverty; almost 40 percent are to women who are unemployed or in part-time positions; and over 40 percent are to women under age 25.

The average cost of having a baby is more than one-fifth of the average pre-tax income of a couple in their early twenties where both persons work. Moreover, four out of 10 births are unintended so that women and families do not have the opportunity to accumulate savings or ensure adequate health insurance coverage.

FINANCING SYSTEMS

Most families rely on insurance to finance maternity care. Seventy-three percent of women of reproductive age have some form of private health insurance; 67 percent have employment-related insurance, and an additional six percent have nongroup coverage (policies unrelated to employment). Ten percent are covered by publicly financed insurance programs, such as CHAMPUS or Medicaid, and 17 percent have no insurance at all.

Public Programs

Public programs help pay for medical care for about one in five new mothers. The largest of these programs, Medicaid, paid for 17 percent of all births (630,000) in 1985 but, because eligibility standards for Medicaid vary so dramatically from state to state, the proportion of all births covered by the program differs drastically. In 1985, it ranged from three percent in Alaska to 25 percent in Michigan. Some of these state-to-state differences in access to Medicaid-funded maternity care are being removed as a number of states have opted to expand Medicaid for pregnant women with incomes up to the federal poverty level. According to testimony of the National Governors' Association before this committee in March, 35 states have chosen to provide this coverage. We hope that states will respond as enthusiastically to the option to cover women up to 185 percent of poverty -- but we fear they may not. Until the federal government mandates coverage of pregnant women up to certain income levels, these state-to-state inequities will persist. S.2122 and S.2046 are important steps in that direction.

It is critical, however, that efforts to expand Medicaid coverage be accompanied by efforts to improve the actual operation of the program. Historically, Medicaid benefits have been linked to receipt of cash assistance, and Medicaid has generally been administered by the welfare bureaucracy. It is not surprising, therefore, that many states have put great emphasis on limiting access to benefits through stringent eligibility determinations. Now they must concentrate their efforts on reaching out to make sure all those who qualify are included. Some states are stepping up their outreach efforts as they begin to implement the Medicaid expansion, but unless they launch major recruitment campaigns, the promise of an expanded Medicaid program will not be fulfilled.

The process of applying for Medicaid is so slow and cumbersome as to almost preclude entry into prenatal care in the first trimester of pregnancy. Once a woman finds out she is pregnant and decides to apply for Medicaid, she must fill out an application form that rivals -- and sometimes exceeds -- the IRS forms in complexity. These forms average 14 pages, but can run to as many as 40. Completing an application, together with the required documentation, usually entails several visits to the welfare office. Once the application is completed, it usually takes about a month for the state to determine whether an individual is eligible; in many states it takes longer. Steps taken by Congress recently to encourage simpler applications for pregnant women by waiving questions about resources, and to enable providers to claim reimbursement for services provided to pregnant women who they expect to be eligible for Medicaid -- so-called "presumptive eligibility" -- are important, but they are being implemented in relatively few states.

Another critical issue that needs to be addressed is that of physician participation in Medicaid. Due largely to the escalating costs of malpractice insurance, many obstetrician-gynecologists no longer practice obstetrics. In addition, 44 percent of physicians providing obstetric services will not accept Medicaid payments for delivery. One of the main reasons for this is low reimbursement. In 1986, physician fees for a regular delivery averaged $830 but Medicaid reimbursement averaged only $554. In New Hampshire, Medicaid paid only $216, while in neighboring Massachusetts the payment was $1,027. Even if reimbursement rates were raised in all the states, the bureaucratic red tape involved in dealing with Medicaid will still deter many providers from participating.

If Medicaid is to be made to work well for pregnant women who are not on AFDC, the program's availability must be widely known, the program's administration and the determination of eligibility must be visibly separated from public assistance so as to remove the stigma associated with receipt of Medicaid or welfare benefits, the application process must be quick and easy and participation by providers must be broadened by making it attractive.

Public programs other than Medicaid also play an important role in providing access to maternity care, particularly by supporting a network of clinics to which women can go for services. Two of the largest of these programs are the Maternal and Child Health Block Grant, which, of course, is in this Committee's jurisdiction, and the community and migrant health center programs, which fall under the Labor and Human Resource Committee. While these programs provide a range of primary care services to women and others, in 1986 they provided prenatal care to an estimated 660,000 women (447,000 in MCH clinics and 213,000 in community and migrant health centers). These clinics were a major access point for prenatal care for Medicaid patients and the uninsured: a third of these patients were covered by Medicaid and almost six out of 10 were uninsured.

Since the MCH Block Grant, like Medicaid, is administered by the states, eligibility varies widely, from 100 percent of poverty to 300 percent or higher. There is no clear pattern, however, which would show that MCH Block Grant funds are being used to iron out state-to-state differences in coverage under Medicaid. Moreover, four states states have chosen not to use their MCH block grant funds for prenatal care* and four of the states that do provide prenatal care serve only high-risk patients,** while two serve only low-risk patients.***

MCH and community and migrant health centers do much to provide access to prenatal care, but they are of very limited assistance when it comes to the hospital bill for delivery -- which accounts for the bulk of the cost of maternity care. Only six percent of women who got prenatal care from MCH Block Grant-supported clinics and three or four percent of those who got care from community or migrant health centers received help with the hospital bill -- and even then the contribution was usually modest. Furthermore, clinics appear to provide very limited assistance to women in securing hospital admission for delivery.

Private Health Insurance

Since maternity care historically was viewed by insurance companies as a "predictable event," and therefore not suitable for insurance against actuarial risks, many private health insurance plans excluded maternity. In 1978 Congress enacted the Pregnancy Discrimination Act (PDA) that requires most employers, including self-insured employers, to cover pregnancy-related services in the same way as other medical services are covered. While the effects of the PDA in extending coverage of maternity care have been dramatic, the law has several important loopholes. First, it does not apply to the three million women of reproductive age who have nongroup policies. Second, the law only guarantees coverage to the employee and the employee's spouse, and not to a nonspouse dependent such as a teenage daughter. Third, the PDA does not apply to firms that employ 15 or fewer workers. Largely as a result of these three loopholes, about nine percent of women of reproductive age--some five million women--have private health insurance that does not cover maternity. Each year, approximately 333,000 women who have babies have private insurance coverage that does not cover their maternity care.

All states require that newborns be covered under their parents' insurance policies from the moment of birth. However, these laws have two important drawbacks that can preclude needed coverage in some cases. First, the state laws generally apply to coverage of illness, but not to in-hospital well-baby care (which may extend to several days if the mother has had a cesarean delivery or other complications of childbirth). Half of typical group policies do not cover routine physician care of newborns in the hospital. The second problem is that the federal PDA does not require that the pregnancy of a nonspouse dependent be covered, and state newborn laws--since they apply only to newborn infants of employees and their spouses--do not require coverage of the newborns born to nonspouse dependents. Consequently, only 25 percent of typical private insurance policies cover both the pregnancy of a teenage daughter and the care needed by her newborn baby.

Private health insurance has other shortcomings as a financing mechanism for maternity care. Most insured women are in policies that require either a waiting period before coverage can begin or before pre-existing medical conditions, such as pregnancy, are covered. Only a fraction of insurance policies pay for the full cost of the care that is needed by a pregnant woman; more than nine in ten insurance plan participants have coverage that is limited by deductibles, copayments or maximum insurance payments. In addition, plans do not always cover all necessary care. For example, 14 percent of typical policies do not cover rho-gam injections for a pregnant woman.

Women Without Insurance Coverage For Maternity Care

Some, but not all, women who had no insurance protection before becoming pregnant may find themselves eligible for Medicaid once pregnant. Whereas, at any time, 26 percent of all women have no insurance for maternity care, at the time of delivery, just 15 percent are uncovered. Each year, 555,000 women give birth with no insurance coverage for maternity. Teenage mothers and those in their early twenties are most likely to lack insurance coverage for delivery.

Uninsured women are more likely than insured women to obtain insufficient prenatal care. They are also more likely to face obstacles to hospital admission at the time of delivery. Women who have no insurance may be asked to pay a pre-admission deposit of between $500 and $1,000. In the past, some private hospitals were reported to have refused to admit uninsured patients. In 1986, a federal law took the first step toward ending this practice by prohibiting hospitals from "dumping" uninsured women who are in "active labor." Unfortunately, the law does nothing to prevent hospitals from refusing women who are in the early stages of labor or who have complications during pregnancy.

The fact that so many women having babies have no insurance for their maternity care also has grave implications for medical providers, who are affected by the complexity of arranging and financing the services needed by their patients. While some women may forego prenatal care in the absence of insurance, almost all deliver in hospitals. Thus, maternity and newborn care account for 27 percent of all uncompensated hospital care in the United States. Since there is no orderly

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third-party payment system for this care, the cost is being shifted, in a disorganized and haphazard way, to federal, state and local governments, insurance companies and Blue Cross/Blue Shield plans, employers who insure their employees and, ultimately, employees and taxpayers. In short, this care is being delivered, and we are all paying the bill.

CONCLUSION

Although Congress and the states have made much progress in the past decade toward improving access to maternal and child health services, much remains to be done. Some of the immediate steps that need to be taken include:

- Requiring coverage for maternity care of all women insured under private policies and coverage of all newborns from the moment of birth;
- Mandating Medicaid coverage for women with family incomes below 185 percent of the official federal poverty standard and above that level, gradually expanding Medicaid to cover maternity and newborn care for those who cannot purchase private insurance, with premiums graduated on the basis of a family's ability to pay;
- Requiring states, or providing financial incentives to them, to make aggressive efforts to inform poor women about the availability of Medicaid subsidy for maternity care; to process Medicaid applications in such a way that care can begin in the first trimester of pregnancy; and to offer providers reasonable reimbursement for maternity and newborn care;
- Establishing state eligibility systems for maternity and infant care that are divorced from the welfare system;
- Strengthening community-based clinic services and improving their connections with hospitals for delivery, to assure continuity of care; and
- Improving access to family planning services, particularly for low- and marginal income women and teenagers, to reduce the incidence of unplanned pregnancy.

If all of these recommendations were adopted throughout the country, and fully implemented, the current system could be made to work much better than it now does. Realistically, however, it will be many years until they are adopted by Congress and all the states -- and that day many never come.

If, therefore, our goal is to make certain that all women have access to at least basic maternity and infant care, an alternative approach would be to create an entitlement to these services, in much the same way as we have created an entitlement to health care for the elderly through Medicare. Such a system would be less cumbersome and expensive to administer than the many different systems currently employed. It would eliminate the state-by-state variations in eligibility and benefits inherent in the Medicaid program, and also circumvent the stigma attached to programs designed and administered with only welfare clients in mind. Most of the expenses of maternity and infant care are already being paid by somebody -- the only "new" expenses of a nationwide system would be for early prenatal care. However, these expenditures are relatively small and would undoubtedly save money in the long run by improving the health of new mothers and newborns. Such a universal system could be financed through a combination of public and private revenues and be administered under the auspices of the federal government, as are Medicare and Social Security. It would provide a basic, uniform benefit package with built-in cost control provisions, and would cover all pregnant women and their babies, regardless of family income.

Adequate and effective financing would not solve _all_ the problems of ensuring access to care, neither would it be reflected in an immediate decline in infant mortality -- but it would help considerably. We believe it is unconscionable that we as a society appear to care so little for the next generation that we cause couples to hesitate about having a baby for fear they cannot afford proper medical care, and place obstacles in the way of pregnant women who seek and need such care.

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* Alaska, Montana, North Dakota, Wyoming
** Hawaii, Idaho, Minnesota, South Dakota
*** Louisiana, Virginia

1. Introduction

FINANCING MATERNITY CARE IN THE UNITED STATES

Giving birth to a child is an almost universal human experience, a process associated in the minds of most people with joy and fulfillment—the proverbial blessed event. But most societies know that pregnancy and childbirth are not without risks—risks that are sometimes serious and, occasionally, even fatal. Medical monitoring and the provision of nutritional, educational and other support services and health care before, during and after the birth are, therefore, essential to ensure the best possible outcome for the mother and her baby.

There is evidence, however, that not all Americans can take high-quality maternity care for granted. In some parts of the country, distance from a doctor or hospital is a problem; in others, medical personnel are in short supply. Some physicians are unwilling to accept high-risk patients, out of fear of expensive malpractice suits. Other doctors are reluctant to accept poor patients if they anticipate that their bills will not be paid, or that they will receive inadequate reimbursement from public insurance programs.

Not all the shortcomings in maternity care are attributable to the service delivery system. Some pregnant women fail to appreciate the need for early prenatal care, or the importance of changing behavior—such as smoking or drug use—that may endanger their own health and that of their babies. Some women are unwilling to admit they are pregnant until the signs become unmistakable, thus delaying needed medical care.

Clearly, one important factor that contributes to the inability of many expectant mothers to obtain appropriate maternity care in a timely manner is the cost of having a baby. Even if the pregnancy and birth are uneventful, the charges are high, and if there are complications, a young couple without health insurance can be faced with bills amounting to more than they earn in an entire year. Although most people have insurance that covers the costs of maternity care, many people do not, or their coverage is inadequate.

The Financing System for Health Care

Maternity care, like general health care in the United States, is paid for by a mix of private health insurance, public financing systems and out-of-pocket payments by the patient and the patient's family. Coverage, however, is by no means universal. Some 35 million Americans under age 65 in 1984 had no health insurance of any kind, and that number is rising.[1] In the late 1970s, 13–14 percent of people under age 65 had no insurance; by 1984, that fraction had increased to 17 percent.[2]

There are several reasons why a large and increasing number of Americans lack health insurance. First, because most private insurance is linked to employment, many young people who are out of school, but are not yet steadily employed, are not covered. People employed in service industries or in small or marginal enterprises are likely to have no insurance at all, or to have only very limited coverage. Unemployed people and individuals who have recently changed jobs often have no insurance. A married woman who is not working may not be covered by her husband's plan, or his plan may not include maternity benefits. What is more, employers, faced with skyrocketing costs for medical care, have been cutting back on the scope of the benefits they offer, restricting coverage of employees' dependents and insisting on larger deductibles and copayments from their plans' participants. Perhaps even more important, some employers are discouraged by the high and rising costs involved, and by the increased administration required because of burgeoning government regulation in the insurance field; as a result, they are not offering their employees health benefits at all.

Eligibility for Medicaid, the major governmental health program for the poor, is generally linked to eligibility for welfare payments. Historically, the government has been more concerned with keeping ineligible persons out of the welfare system than with reaching out to those who may need services. What is more, Medicaid, like welfare, is administered by the states, and the criteria used to establish who is eligible, as well as levels of support for people judged to be eligible, vary widely with the historical, political and economic conditions peculiar to each state. Efforts to reduce these inequities are complicated by the fact that some states, in response to shrinking budgets and cuts in federal allocations, have tended to curtail eligibility, to keep levels of reimbursement to physicians and hospitals low and to discourage recipients' use of medical services.

Financing Maternity Care

Obtaining adequate financing is especially difficult for women seeking maternity care. One reason is that women having babies tend to fall into those age-groups and income categories that are most likely to be without health insurance. They tend to be young (almost half are under age 25[3]) and to be employed in entry-level, low-paying jobs with few fringe benefits, or in part-time jobs with no such benefits. Another contributing factor is that, whereas private insurance evolved from society's perceived need to protect individuals from the economic consequences of unforeseeable, acute illness and injury, maternity care was generally considered to be just the kind of preventive, predictable and long-term type of care traditionally excluded from insurance coverage. In 1978, Congress sought to improve coverage of maternity care under employment-related insurance plans by passing the Pregnancy Discrimination Act. Even today, however, many restrictions—such as waiting periods for private insurance coverage and complex and time-consuming eligibility determinations under Medicaid—tend to obstruct attainment of the widely accepted societal goal of having women begin prenatal care as early in the pregnancy as possible in order to improve their chances of having a healthy baby. Similarly, under both private insurance and Medicaid, the kinds of payment systems found and, especially, the ways these systems are administered, emphasize treatment for episodic illnesses and injuries, rather than the type of preventive and continuing care required in pregnancy.

When people who have no insurance need medical care, they must depend on their own resources. Some assume large debts, which may or may not be paid. If not paid fully, the burden of the unpaid portion–called uncompensated care–falls first on the health care providers, but, ultimately, on the taxpayer at the federal, state or local level, or on employers and employees through increased health insurance premiums. Because women of reproductive age are less likely than most other people to have health insurance, and because medical technology has made it possible to save very immature or severely ill infants—albeit at a very high cost—a substantial proportion of the uncompensated care burden carried by society is the result of hospital services provided to maternity patients and their babies.

Falling Through the Cracks

This publication shows graphically how the current crazy quilt of programs and policies through which maternity care is financed in the United States has left nearly 15 million women of reproductive age uncovered by private or public insurance programs for maternity care. More than half a million women who have no coverage give birth each year; these births represent 15 percent of all that occur. Although nearly all expectant mothers eventually deliver in hospitals, a substantial number arrive there with no records, having had little, and sometimes no, prenatal care, and are cared for by doctors who have never seen them before. Many will have faced a host of obstacles during pregnancy that could easily turn what is supposed to be a happy event into a period of extraordinary stress for themselves and their families. Such obstacles may also lead to unnecessary and dangerous complications for the mother and infant. These complications, in turn, can result in considerable financial costs for the individuals involved—and for society—to pay for the intensive curative care required to compensate for the preventive care that was not provided during pregnancy.

Recent studies have illustrated the health benefits to the mother and her child that are derived from high-quality prenatal and obstetric care, and the financial benefit to society of providing such care.[4] Inadequate or insufficient care may be one reason that the infant and maternal mortality rates and the percentage of low-birth-weight babies born in the United States are higher than those recorded by other industrialized countries. The U.S. infant mortality rate is almost twice the rate of Finland, Japan and Sweden;[5] the maternal mortality rate is 60–70 percent higher than that of Canada and most Scandinavian countries;[6] and the percentage of newborns weighing under 2,500 g (approximately 5.5 pounds) is twice as high in the United States as in Norway.[7] The U.S. Department of Health and Human Services now projects that its published national goal of achieving substantially improved outcomes for America's pregnant women and their babies by 1990 will be impossible to meet.[10] Although we are very good in the United States at saving the lives of low-birth-weight babies, we are clearly not as successful as other countries in preventing the occurrence of the condition in the first place. Of special concern is the uniquely poor pregnancy outcomes experienced by the most vulnerable in our society—the poor, the very young, minorities and the unmarried.

Financing problems, of course, are not the only reasons for the maldistribution and inadequate provision of maternity care services in the United States. Another problem is the lack of an agreed definition of what the most important components of high-quality maternity care consist of, beyond very basic care. In particular, the relative value of some of the newer technological interventions—the value of ultrasound, for example, to determine fetal position and diagnose fetal defects, as compared with that of such behaviorally oriented interventions as antismoking programs or nutrition counseling—is a matter of controversy. (Even where there is agreement on the necessity of a treatment or procedure—the injection of rho immune globulin, for example, to save the babies of Rh-negative mothers—insurance does not always cover the cost.) And no matter how maternity care services are financed, there has clearly been a failure to expand, or even maintain, networks of health facilities at the community level that are capable of extending care to all who need it. The withdrawal of physicians from obstetrics practice—believed to be largely because of the rising cost of malpractice and liability insurance—is also reason for increasing concern.

Notwithstanding all these other problems, a more rational system of financing maternity care would increase the early and appropriate use of prenatal services and thereby contribute to the health of women and their babies. It would also help reduce the stress, discontinuity of care and humiliation that so many women and their families must now face in order to obtain the help they need.

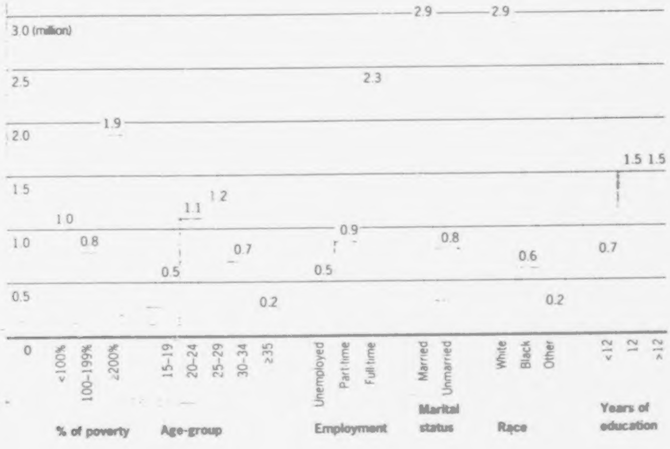
2. Having a Baby in America

Most women start having babies when they are in their 20s and when their family income is modest

Some 3.7 million women—about seven percent of all U.S. women of childbearing age—have a baby each year. Although women are having fewer children than they used to, eight out of 10 will have at least one child, and mothers typically have had two or three children by the end of their reproductive years.[9]

Most women have babies when they are young and their family income is modest. The typical woman who gives birth is in her 20s, is married, has an annual family income of just under $20,000, has at least a high school education, and is employed, or married to a man who is employed, full-time.[10] About four in 10, however, are unemployed or work only part-time; more than one-quarter are poor* and four in 10 have family incomes of less than $15,000 a year. The proportion of babies that are born to unmarried women, to women over age 35 and to blacks—population groups considered at higher-than-average risk of adverse birth outcome—has been rising, whereas the proportion born to teenagers and to women with less than a high school education—also considered high-risk groups—has been declining.[11]

Number of women who give birth, by selected char- [illegible]



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*The term "poor" refers to individuals whose family income is below 100 percent of the federal poverty level—$9,300 for a family of three in 1987. (See: Federal Register, Vol. 52, No. 34, Feb. 20, 1987, p. 5340.)

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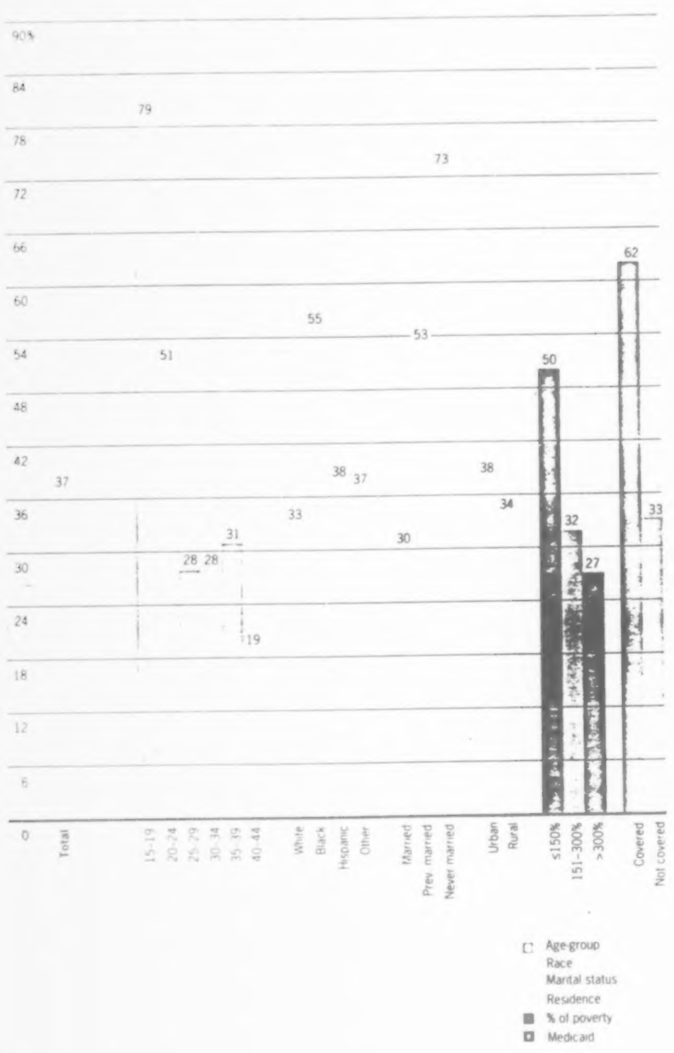
Most births to teenagers, the unmarried, the poor, blacks and those on Medicaid are unplanned

The number of babies born every year in the United States has varied little during the 1980s.[12] Although childbearing is fairly predictable from an actuarial point of view, it is much more difficult for an individual woman to anticipate the likelihood that she will become pregnant in any given year. As a result of this uncertainty, when she learns she is pregnant she may not have made financial plans to cover the costs of having a baby. Surveys show that every year, about four in 10 births were not planned at the time of conception. Among teenagers, never-married women and those on Medicaid, more like 6–8 in 10 births were unplanned. The level of unintended births is also very high among women in their early 20s, blacks, previously married women and those of low income (about $9,300 in 1987 for a family of three). Even among women who are in their late 20s and 30s, married and more affluent, about 30 percent of births are unplanned.[13] (The proportion of unplanned pregnancies is, of course, much higher, as evidenced by the 1.5 million abortions that occur in the United States each year.[14])

7



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8 Of 14 million hospital patients aged 15-44, 3.7 million are women giving birth

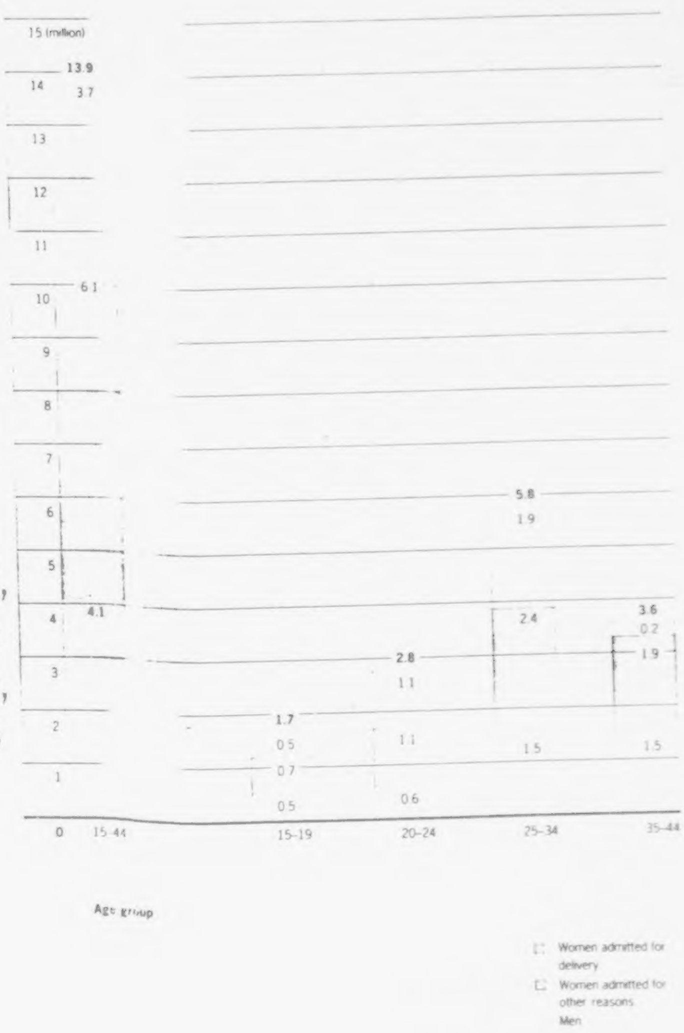
In 1985, 13.9 million men and women aged 15–44 were hospitalized for all causes (other than long-term care). Of these, 3.7 million (27 percent) were women having babies; and 6.1 million were women admitted for other reasons, including 1.2 million admitted for reproduction-related reasons.*[15] The number of women admitted to hospitals to have a baby or for another reproduction-related reason (4.9 million) exceeded the total number of men admitted for any reason (4.1 million).

Women admitted for delivery accounted for 1.1 million (39 percent) of the 2.8 million hospital patients in their early 20s, 1.9 million (33 percent) of the 5.8 million aged 25–34, about 500,000 (28 percent) of the 1.7 million teenage patients, and 200,000 (six percent) of the 3.6 million patients aged 35–44. For each age-group, the estimate of the degree to which hospital care is dominated by reproductive health care would obviously be even higher if women receiving treatment for other reproduction-related reasons were also included.

Complications of pregnancy, childbirth or the puerperium (the period of confinement after labor); abortions; ectopic pregnancies or molar pregnancies (pregnancies that turn into an abnormal mass); disorders of menstruation and other abnormal vaginal bleeding; and sterilization.

9

Number of women admitted to short-stay hospitals, by whether admission was for delivery, and number of men admitted, according to age-group, 1985



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Pregnancy and childbirth are relatively safe, but 6 in 10 mothers have some health problem–half of them are major

Because pregnancy is so often unpredictable, it can be disruptive and involve unexpected costs. From a physical point of view, however, pregnancy and childbirth is a very safe experience for most women. Only about eight women in every 100,000 die from complications associated with childbearing (although the mortality rate among black women is three and one-half times greater than the rate among whites).[16] However, the experience is not risk-free. Just four in 10 mothers go through pregnancy and childbirth without any medical problem, while six in 10 are treated for some complication. Three in 10 are reported by their physicians to have had major complications,* which can result in considerably increased costs of medical care.

Doctors report that nearly one in seven mothers have problems during pregnancy, and about nine in 10 of those problems are major. Some of the more common of the major problems are conditions that may result in the early onset of labor; conditions that can cause fetal distress; multiple pregnancies; and infections of the genitourinary tract.

Overall, the most common health problems—experienced by three in 10 mothers—are complications that occur during labor or delivery: umbilical cord complications; obstructed labor; breech (feet-first) presentation of the baby; severe lacerations of the perineal muscle, cervix or vagina; and severe postpartum hemorrhage. Slightly over one-third of all complications during this period are considered major.

More than one in seven mothers have health problems related to preexisting conditions, such as disproportion or abnormality of the pelvis (which usually results in a cesarean delivery), infectious diseases, high blood pressure, anemia, diabetes or Rh incompatibility; four in 10 of these problems are considered major.[17]

Thirty-six percent of women who have any complication during pregnancy and delivery experience more than one problem. About two out of every 10 mothers are delivered by cesarean section,[18] and almost half of these procedures, according to the women's doctors, are performed because of serious pregnancy complications. (Previous cesarean delivery, the reason given for about one-third of all cesarean sections performed in 1985, is not considered to be a serious complication.)

Understandably, health problems in pregnancy and childbirth are more common among the vulnerable subgroups already mentioned, such as teenagers, the poor and older women. An illustration of this tendency is the fact that 41 percent of mothers under the age of 35 have experienced an uncomplicated pregnancy and delivery, compared with only 33 percent of mothers 35 and older.[19]

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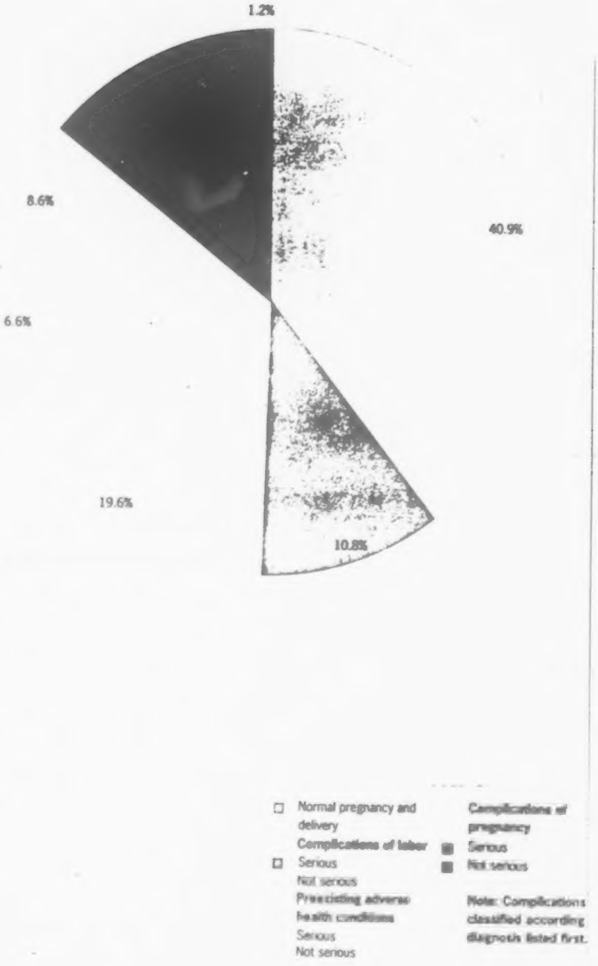
*Most of these estimates are based on tabulations of data from the National Center for Health Statistics and from the 1984 National Hospital Discharge Survey. Major complications, or potentially serious health problems for the mother or the newborn, are difficulties attendant on pregnancy and childbirth that involve considerably more than the average amount of medical care and, in some cases, hospitalization.

Percentage distribution of mothers, by whether a complication occurred during pregnancy or delivery, 19[illegible]



Note: Complications classified according diagnosis listed first.

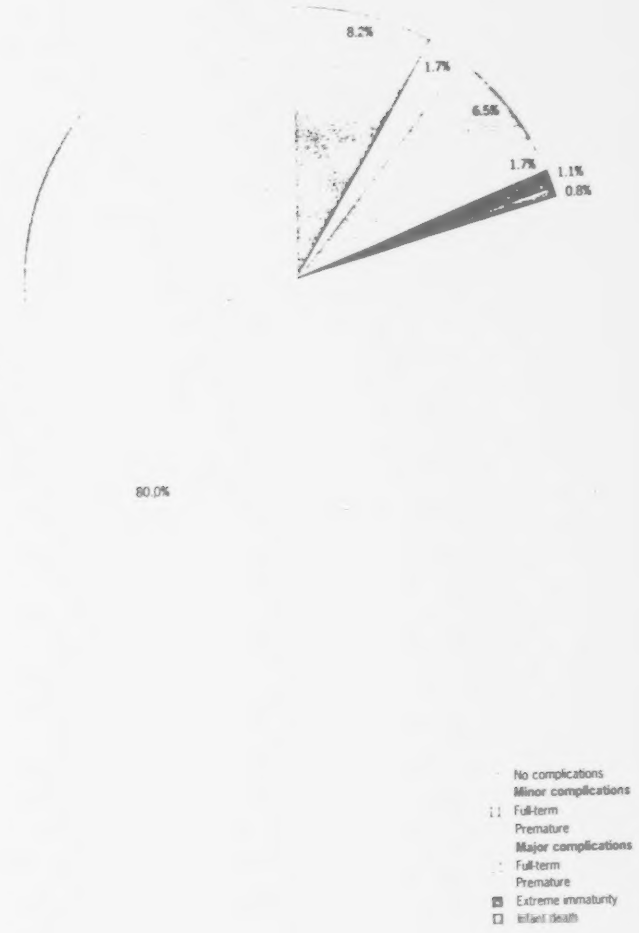
12

Most babies are born healthy, but 770,000 each year have health problems; 335,000 have major problems

Most newborns are healthy. But about 20 percent—some 770,000 each year—are born with a health problem. About 335,000—10 percent of babies born each year—have serious medical conditions, and of these, some 31,000 die in the first month after delivery.[20] About seven percent of all newborns weigh less than 2,500 grams.[21] Such low birth weight is the major factor associated with infant mortality.[22] Twenty percent of white babies, but 25 percent of blacks, are born with a health problem;[23] in the first year of life, the rate of death among black infants is two times higher than the rate among whites.[24] The prevalence of low birth weight has not declined during the 1980s, and the infant mortality rate has declined only slightly.[25]

Poverty increases the risk of poor birth outcomes, especially if it accompanies other characteristics that are associated with health disadvantage.[26] Slightly more than one-quarter of all births in the United States occur among poor women. Four-fifths of unmarried women, two-thirds of blacks, three-fifths of teenagers and two-fifths of Hispanics who give birth are living in poverty.[27] Birthrates are about twice as high among poor as among nonpoor women, and are 30 percent higher among black women than among whites.[28]

A G A
PRE-TERM



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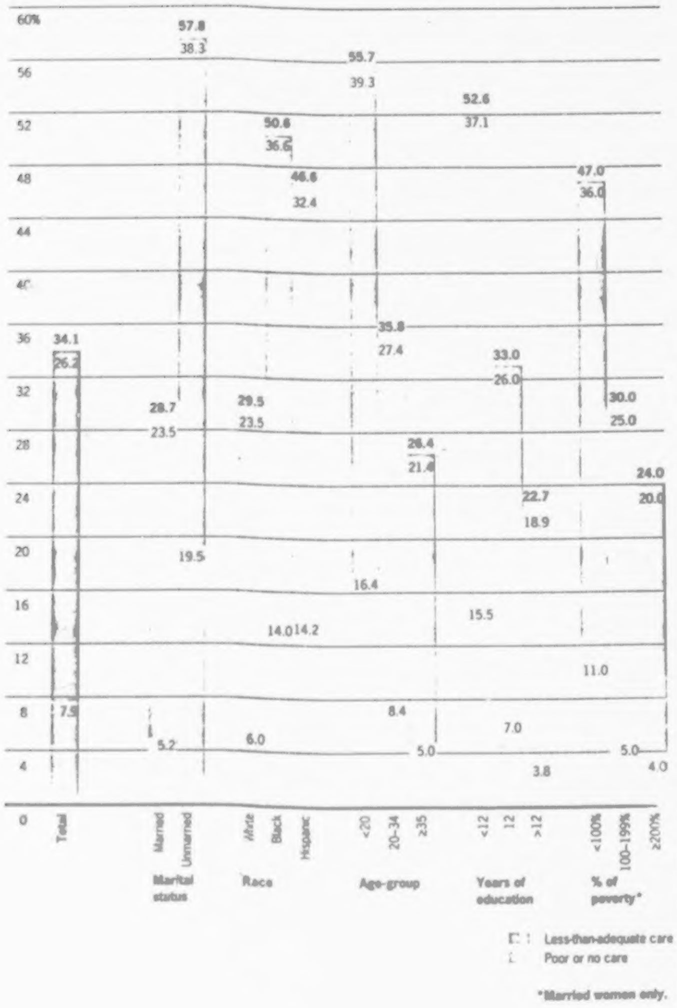
14

One-third of mothers get insufficient pregnancy care; proportion is highest among teenagers,the unmarried, blacks

There is general agreement that prenatal care should begin early and that it should continue throughout the pregnancy. It is nevertheless clear that many women are not obtaining prenatal care early enough, do not make enough prenatal visits, or do not get care throughout pregnancy. Some get no care at all. Thirty-four percent of pregnant women—some 1.3 million each year—are getting what is generally considered insufficient prenatal care.[*] Some 662,000 do not begin care until the second trimester of pregnancy; 207,000 do not start until the third trimester or get no care at all; 393,000 initiate care in the first trimester but make very few prenatal visits.[29] The percentage getting insufficient care is highest among the unmarried (58 percent), teenagers (56 percent), the least-educated (53 percent), blacks (51 percent), Hispanics (47 percent) and the poor[†] (47 percent).[30] Women make an average of 10.5 prenatal visits,[31] somewhat fewer than the 13 that are recommended by the American College of Obstetricians and Gynecologists.[32] (In 1985, this goal was reached by only 28 percent of expectant mothers.[33]) Although there is no consensus on the optimum number of visits, the importance for the mother's and the infant's health of beginning care in the first trimester of pregnancy is widely recognized,[34] and the U.S. Surgeon General has set a goal of early prenatal care for 90 percent of expectant mothers by 1990.[35] However, since only 76 percent are now starting prenatal care in the first three months of pregnancy,[36] it is unlikely that this goal will be met.

[*] *The findings in this section are based on statistics from the 1980 National Natality Survey, with estimates adjusted to the number of births in 1986. For the purposes of this publication, insufficient care is made up of two categories: poor or no care and less-than-adequate care. Care is considered poor if it started in the third trimester, or if there had been only one prenatal visit and gestation was 22–29 weeks, two visits and gestation was 30–31 weeks, three visits and gestation was 32–33 weeks, or four visits and gestation was 34 weeks or longer. Care is considered less than adequate if the first visit did not occur before the second trimester, or if there were only three prenatal visits and gestation was 22–25 weeks, or four visits and gestation was 26–29 weeks, or five visits and gestation was 30–31 weeks, or six visits and gestation was 32–33 weeks, or seven visits and gestation was 34–35 weeks, or eight visits and gestation was 36 weeks or longer.*

[†] *Married women only.*



*Married women only.

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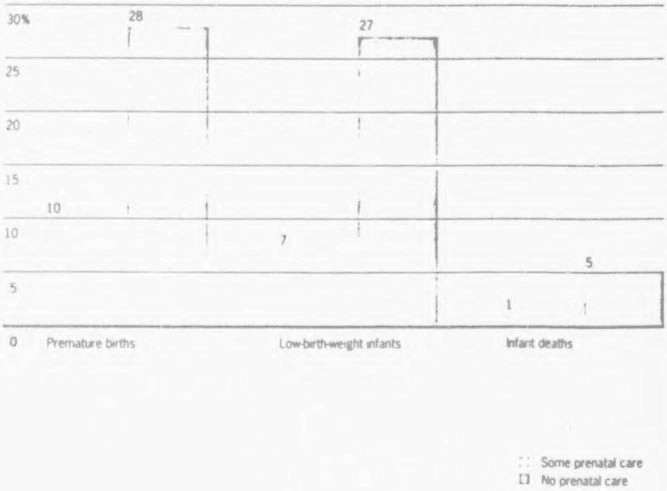
> Women who get insufficient prenatal care have double the risk of having a low-birth-weight baby

Women who do not obtain sufficient prenatal care are about twice as likely as those who do to have a low-birth-weight baby (10 percent vs. five percent); they also are more likely to have their baby prematurely (13 percent vs. eight percent) and to gain too little weight during pregnancy (28 percent vs. 21 percent).[37]

A woman's birth outcome is most likely to be adverse if she does not see a physician until she is in labor. Thus, 10 percent of women who get at least some prenatal care, compared with 28 percent of those who do not, have premature births; and seven percent of those who obtain care, compared with 27 percent of women who do not, have low-birth-weight babies.[38] The infant mortality rate is 9.7 per 1,000 live births among newborns whose mother began prenatal care in the first trimester, it rises to 12.5 per 1,000 where care was initiated later in pregnancy, and it jumps to 48.7 per 1,000 in cases where the mother obtained no prenatal care at all.[39] (Of course, prenatal care is only one of many factors, including poverty, insanitary housing, having an unwanted birth and poor nutrition, that can adversely influence birth outcomes.)

Fewer than two percent of mothers receive no prenatal care, but the proportion is much higher among the poor, teenagers, blacks, Hispanics, the poorly educated and, especially, unmarried women, who are about seven times more likely than married women to obtain no care at all.[40]



18 The average bill for having a baby is about $4,300, one-fifth of a typical young couple's annual income

Having a baby is costly—the average bill is conservatively estimated at about $4,300; it is about $2,900 even if the pregnancy is uncomplicated, the delivery normal and the infant healthy.*[41] The average is about 40 percent higher in urban areas (where about 75 percent of all U.S. couples live[42]) than in rural areas—$4,670 compared with $3,300. Even this presumably low figure represents more than one-fifth of the typical annual income of a couple in their early 20s ($19,800).[43] (These costs, of course, are only medical costs. They do not take into account other costs like loss of earnings attendant on having a baby.)

When there are health complications, the bill is much higher. The total charges for a cesarean birth average $4,860 when the newborn has no health problems and they average $6,250 if the baby has complications; they rise to an average of nearly $12,000 if the birth is premature and there are major complications. If the infant is extremely immature, the bill can rise sharply, to an average of $27,000, a figure that is more than one-third higher than the typical young couple's annual income. And the total cost can run into the hundreds of thousands of dollars for premature babies with severe problems.

For a normal delivery and birth outcome, the hospital bill—averaging a little more than $1,700—accounts for about 60 percent of the total charges for maternity care. As problems increase, that proportion rises rapidly—to 95 percent (nearly $26,000) in the case of a cesarean delivery of an extremely immature infant, which involves a relatively long hospitalization for the mother and a very long period of extremely expensive intensive care for the newborn.

In 1985, about $16 billion was spent in the United States for maternity care. Of this, an estimated $4.7 billion was spent for physician care and laboratory procedures and $11.3 billion was expended for hospital charges ($6.3 billion for care of the mother, and $5.0 billion for care of the newborn).[44]

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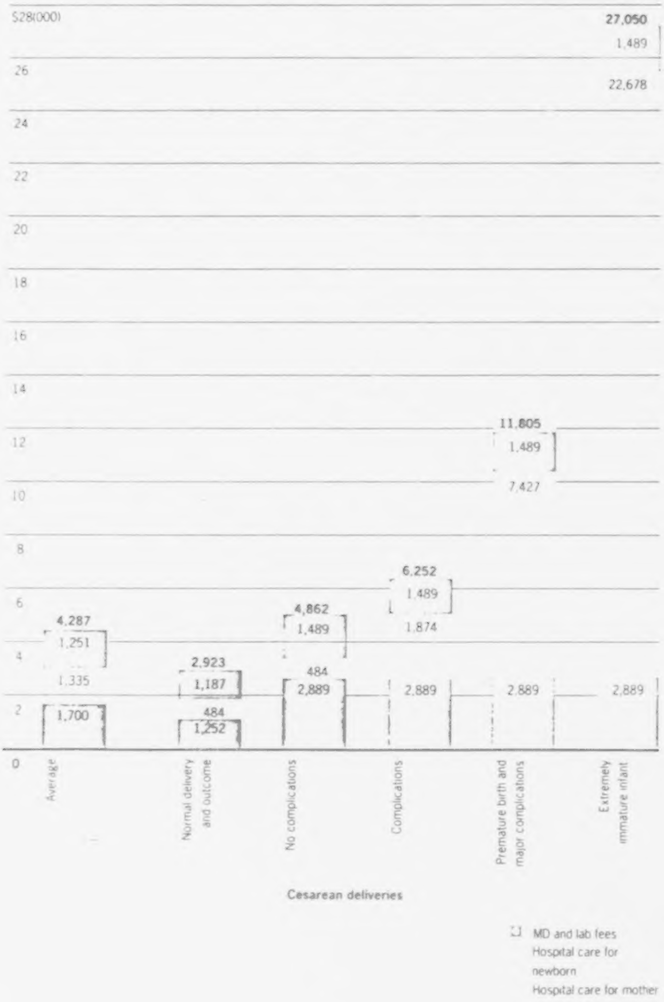
*The charges reported in this section and in Figure 8 are derived from the Commission for Professional Activities' 1985 survey of hospitals, and from the Health Insurance Association of America's 198[illegible] [illegible] survey [illegible] 4.)



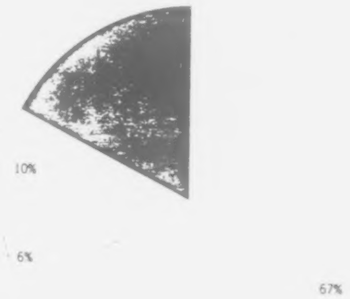
Cesarean deliveries

Private Health Insurance

20 41 million women 15-44 covered by private health plans; 38 million by employment-related plans

Most couples are at least partially insured for the expenses of having a baby. Seventy-three percent of the 56 million U.S. women of reproductive age—41 million—have some form of private health coverage.*[45] Sixty-seven percent—38 million—are covered by group insurance that is generally obtained by their own, their spouse's or their parent's employer,[46] and six percent (three million) buy their health insurance themselves.[47] The latter option is far more costly to the individual than is group insurance, which is usually subsidized by the employer. (In 1986, the average cost of a privately purchased insurance policy was about $2,400, whereas employees participating in a group plan contributed an average of about $156 for an individual policy and $490 for family coverage.[48])

Fourteen percent of participants in employment-related plans (a total of 5.3 million women) are covered through health maintenance organizations (HMOs) or preferred provider organizations (PPOs).[49] HMOs provide most health care to participants, who make specified, regular payments. PPOs are medical groups through which companies contract for reduced rates for their employees' health care. In larger firms, the tendency is for employers or unions to self-insure by organizing their own health-benefit plans for their employees or members. More than four in 10 workers insured through medium-sized and large companies are enrolled in such self-insured plans.[50] Although these self-insured plans are often administered by traditional insurers, they are regarded as benefit packages rather than as insurance plans, and, unlike conventional plans, they do not come under state insurance regulation.



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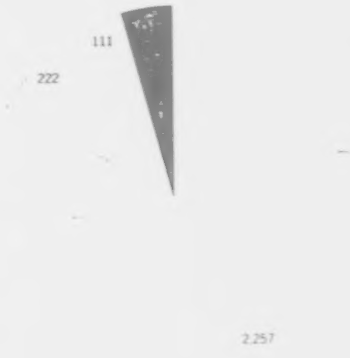
*In order to analyze the extent and nature of employment-related and other private health insurance coverage, The Alan Guttmacher Institute (AGI) made special tabulations of data from the 1985 Current Population Survey of U.S. households and from the 1984 Employee Benefits Survey, conducted by the U.S. Bureau of Labor Statistics, which provides representative data for 21 million full-time employees in private firms, principally those with 100 or more employees. The AGI supplemented this information with a survey in the winter and spring of 1987 of the 100 leading commercial insurance companies and of all 78 Blue Cross/Blue Shield plans. Seventy-three percent of the surveyed

(Continued on page 21)

Five million women 15-44 have private policies that don't cover maternity care

About nine percent of women of reproductive age—some five million women—have private insurance policies that don't cover maternity care. About 64 percent of women who give birth—some 2.3 million women—have their maternity care paid for, at least in part, by private insurance. About 333,000 have private insurance policies that pay nothing for their maternity care, forcing them to rely on their own funds or, if they qualify, to apply for Medicaid.*[51] Many of the gaps in coverage are the result of loopholes in the 1978 Pregnancy Discrimination Act—special legislation that was designed to close some of these gaps. Congress passed this law to require employers to offer employees and their spouses policies that cover maternity care in the same manner as they cover other medical care. However, the law has three major loopholes.

The first and most obvious is that the law applies only to employment-related group insurance; policies that are not employment-related need not cover maternity care. The second problem is that the law applies only to the employee and spouse. As a result, for maternity care, 35 percent of typical family policies exclude nonspouse dependents—in particular, teenage daughters. (There are 2.7 million female unmarried teenage dependents who are not covered by private insurance.[52]) Sixty-nine percent of policies do not cover the babies of nonspouse dependents, whether or not the teenager herself is covered; only 25 percent provide coverage for both the teenager and her infant.[53] The failure to cover teenagers and their babies poses a serious problem, since very young women are at especially high risk of having an adverse pregnancy outcome if they do not get early and appropriate prenatal care. (Eight states do extend to dependent children the same federal protection that is given to the spouses of insured persons.† However, state laws do not affect self-insured plans.) Finally, the law does not extend protection to people insured through firms with 15 or fewer employees.



(Continued from page 20) insurers responded, including 82 percent of the Blue Cross/Blue Shield plans and 66 percent of the commercial insurers. The survey results probably represent the most generous types of policies. The benefits described in this section, therefore, are probably more liberal than average.

* The estimate of five million women aged 15–44 who have private health insurance that does not include maternity care coverage is estimated by comparing health insurance coverage for all women aged 15–44 with the expected source of payment for delivery reported by women giving birth in 1985.

The estimate of 333,000 who give birth each year who have

(Continued on page 22)

Most women are in plans that impose waiting periods; one-fifth are in plans that exclude those already pregnant

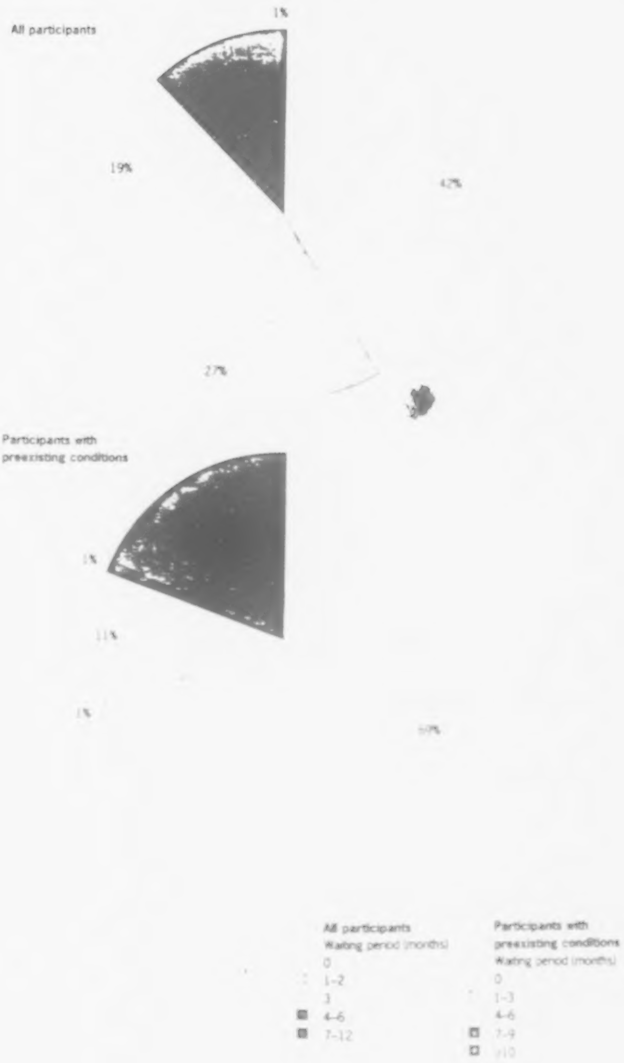
The imposition of waiting periods before coverage begins or before preexisting health conditions are covered may prevent some insured women from getting timely prenatal care. Waiting periods affect new participants in health insurance plans; although relatively few women start a new job while they are pregnant, a husband may well change employment during the course of his wife's pregnancy. (Some women, however, may still be covered by a policy that was in effect at the time the couple conceived.) In addition, changing from individual to family coverage after a pregnancy has begun may entail a waiting period that will delay coverage.

Fifty-eight percent of full-time employees participating in employment-related health insurance programs—including about 20 million women of reproductive age—belong to plans that require a waiting period; more than half of these are in plans that impose a waiting period of three months or longer.[54]

Just over three in 10 participants belong to plans that mandate waiting periods for individuals who have preexisting medical conditions, including pregnancy; 18 percent belong to plans that impose waiting periods of 10 months or more, thus effectively precluding any reimbursement for care during pregnancy.[55]

(Continued from page 21) private insurance that does not cover maternity care was obtained by applying the proportion of women aged 15–44 with private health insurance but no maternity coverage to women giving birth in 1985.

†Illinois, Maine, Maryland, Massachusetts, Minnesota, New York, Ohio and Wisconsin. In order to determine how state laws and regulations affect insurance for maternity care, the AGI compiled information from a wide variety of sources. These include, among others, Blue Cross/Blue Shield, the American College of Obstetricians and Gynecologists, the American College of Nurse-Midwives and the Intergovernmental Health Policy Project of George Washington University. The [illegible] into summary sheets for each state and the District of Columbia. These sheets were sent for verification to each state attorney general. Forty-five states and the District of Columbia responded.


All participants
1%
19%
42%
27%
Participants with preexisting conditions
1%
11%
1%
69%
All participants
Waiting period (months)
0
1–2
3
4–6
7–12
Participants with preexisting conditions
Waiting period (months)
0
1–3
4–6
7–9
>10

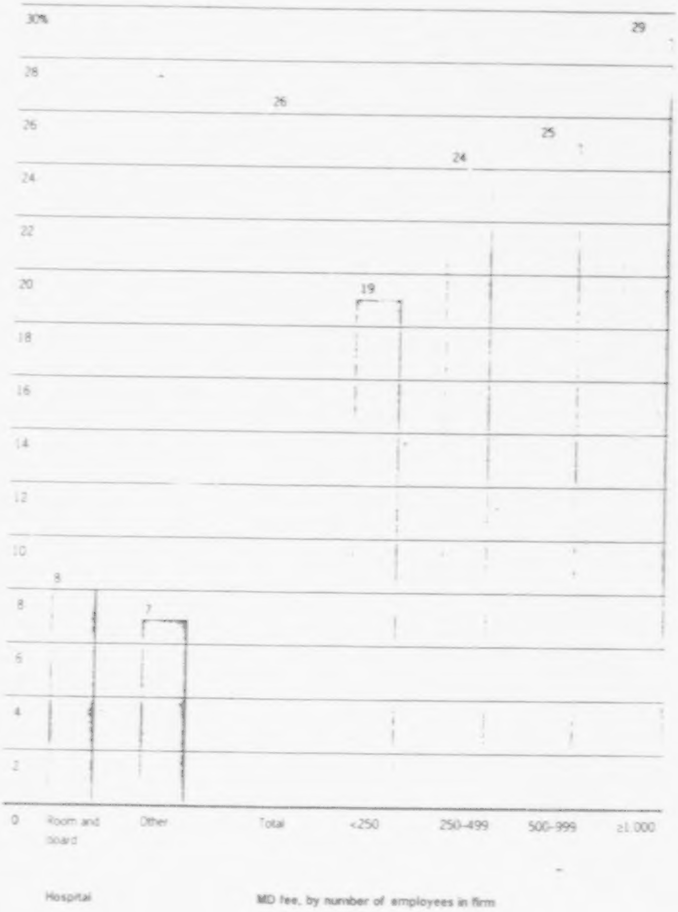
24 Most policies don't pay the full medical bill, and half don't cover routine M.D. care for the baby in the hospital

Maternity care can be expensive for young families, even when they are covered by employment-related plans, because insurance seldom covers the full bill for health care, and it often fails to cover essential services required by expectant mothers and newborns.

The insured employee is usually required to pay a certain deductible amount before coverage takes effect; participants also generally have to pay a percentage of most medical bills (copayments) even after the deductible has been met; and most policies set a maximum reimbursement for each type of service.

Only 7–8 percent of participants in group plans are fully covered for hospital room and board and other charges, such as anesthesia. Only 26 percent are fully insured for physician charges for maternity care. (Among participants in HMOs, however, 92 percent are fully covered for hospital room and board, and 89 percent for the physician's charges.) Coverage for physician fees for maternity care rises with the size of the employing firm. Thus, only 19 percent of people insured through companies that employ fewer than 250 workers have full coverage for their medical bills, compared with 29 percent of those insured through firms with 1,000 or more employees.[56]

Fourteen percent of insurers do not cover Rh immune globulin injections (essential to prevent miscarriage or stillbirth for a pregnant woman whose blood type is Rh-negative). Half do not cover routine physician care of newborns in the hospital. Eighteen percent of insurers limit the number of hospital days allowed for the newborn (typically to three days).[57] Besides costs that are not reimbursed at all, in the course of their pregnancies women must often make payments to the physician for which they are not reimbursed until after they have given birth. This is because the insurer generally makes a single payment to the physician that includes prenatal and postnatal care and delivery. Seventy-five percent of all insurers do not make that payment until after the delivery, and nine percent do not make it until after the completion of postpartum care.[58] More and more physicians appear to be requiring payment for care at the time it is administered, which places the burden of delayed reimbursement on the patient.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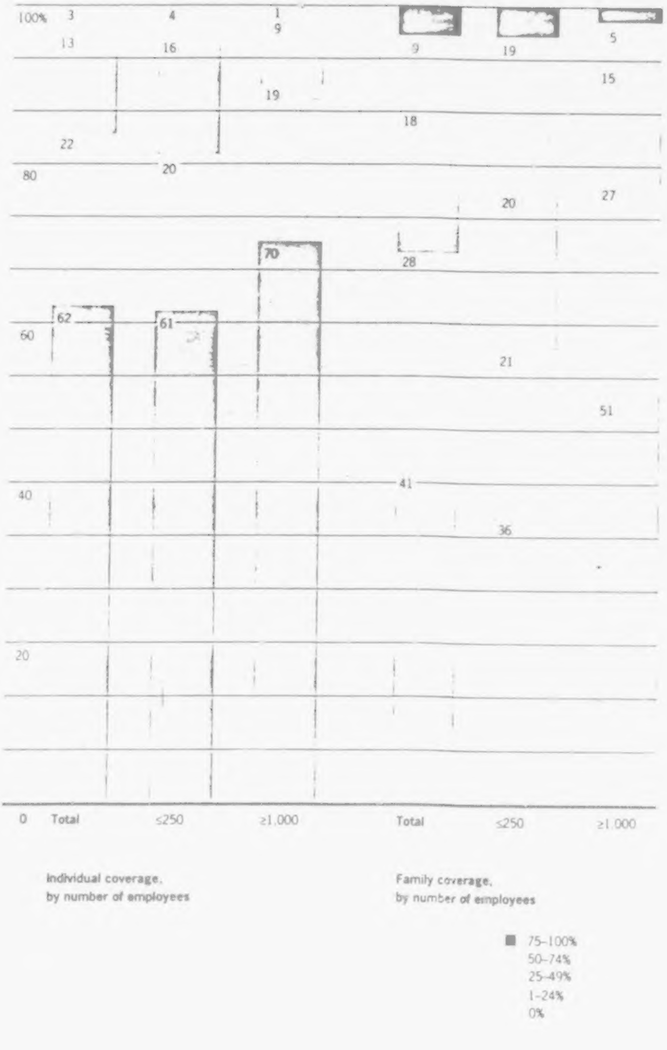
Room and board
Other
Total
<250
250-499
500-999
≥1,000
Hospital
MD fee, by number of employees in firm

26 Six in 10 in employment-related plans must contribute for family coverage

In addition to paying deductibles and copayments, a substantial and increasing proportion of employees must pay for at least part of their health insurance coverage. Overall, 38 percent of participants in group plans were required in 1984 to contribute to the cost of their own coverage, and 59 percent had to pay for part of family coverage.[59] In plans that require employees to contribute, 43 percent of participants must pay for one-quarter or more of the premium for individual coverage; for a family policy, 52 percent must pay that proportion; and 21 percent must pay for half or more.

Employees of small firms not only are less likely than those in large companies to have any health insurance; they also pay more to participate in a group plan, especially for family coverage. Participants in Blue Cross/Blue Shield plans are least likely to be required to contribute to the costs of insurance coverage, and participants in HMOs are most likely to have to do so.[60]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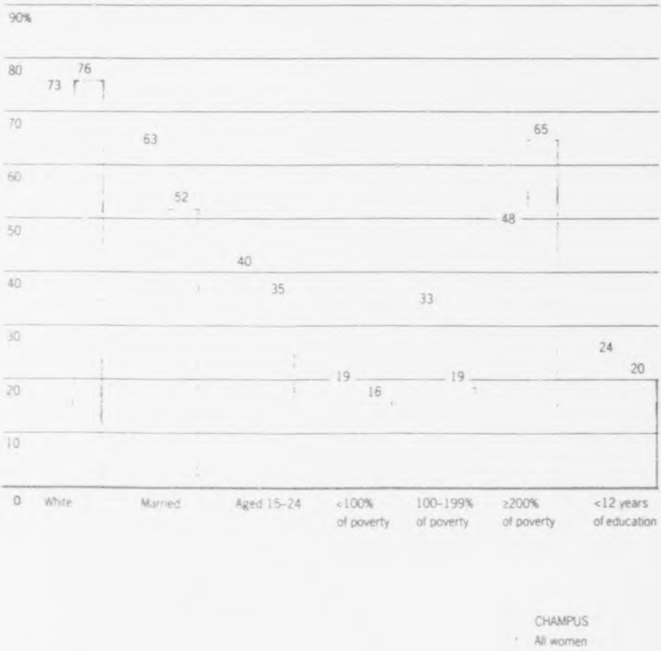
19
20
21
36
5
15
27
51
Total
≤250
≥1,000
Total
≤250
≥1,000
Individual coverage,
by number of employees
Family coverage,
by number of employees
■ 75–100%
50–74%
25–49%
1–24%
0%

28 CHAMPUS covers more than one million women of reproductive age

The Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) is the health program for dependents of those on active duty and for those retired from the U.S. uniformed services and their dependents. Although CHAMPUS is publicly funded, it cannot be considered a public program in the same sense as others discussed in this section, since it is an employment-related fringe benefit and, as such, more closely resembles private health insurance programs. Health care services offered through CHAMPUS are often provided in military hospitals.[61] Some 1.3 million women aged 15–44 are covered by CHAMPUS or—a very small proportion—by Medicare; each year more than 110,000 births are paid for by these programs.

Women of reproductive age whose health care is covered by CHAMPUS have characteristics similar to those of the general population, except that they are more likely than all women in that age-group to be married and to have marginal incomes (less than 200 percent of poverty) and slightly more likely to be under age 25 and to have fewer than 12 years of education. Compared with women whose health care is subsidized by publicly funded programs, however, a larger proportion are white, married, childless and well educated.[62]

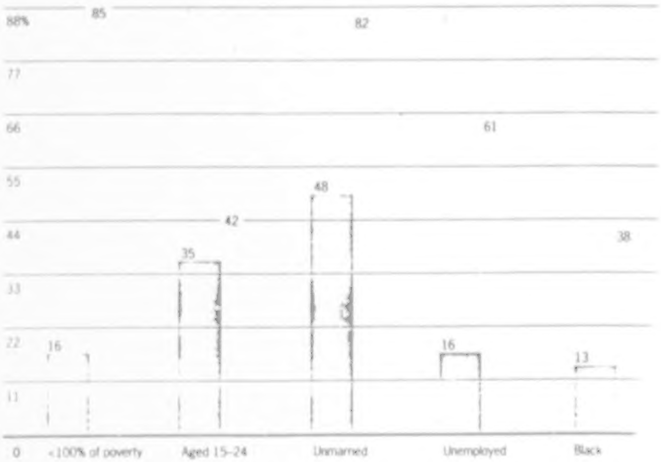


Medicaid covers 4 million women 15-44, 630,000 deliveries annually

Medicaid—the federal-state program designed to finance health care for the poorest of the poor, primarily welfare recipients—is the major source of public funding for maternity care.*[63] Although the program is financed jointly by the federal government and the states, it is administered by the states. The extent of coverage, eligibility criteria, services that are covered and reimbursement levels vary widely, therefore, from state to state.

Just over four million women of reproductive age—the vast majority of them young, unmarried and unemployed—are covered by Medicaid. Almost all have children or are pregnant (generally a requirement for qualification for Medicaid for women in this age-group).[64] In recent years, Congress has given special priority to the needs of poor, pregnant women by requiring coverage for many poor women who would not normally be covered under their states' Medicaid programs.[65]

Medicaid covers medical care for 4.2 million women—seven percent of all women of reproductive age.[66] In 1985, some 630,000 deliveries—17 percent of all births—were subsidized by Medicaid, at a total cost to the federal and state governments of about $1.8 billion.[67] Thus, Medicaid contributes only 11 percent of the $16 billion spent for maternity care nationwide,[68] even though women on Medicaid are likely to have more health problems during pregnancy than the average woman. The proportion of births covered by Medicaid varies widely by state; in 1985, it ranged from three percent in Alaska to 25 percent in Michigan.[69]



☐ All women
Women on Medicaid

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*In November 1985 and in October 1986, the AGI surveyed the heads of the state Medicaid agencies to gather information about maternity services financed through this federal-state mechanism. All states responded except Alaska [illegible] and Wyoming. Most of the data in this section are drawn from the results of that survey.

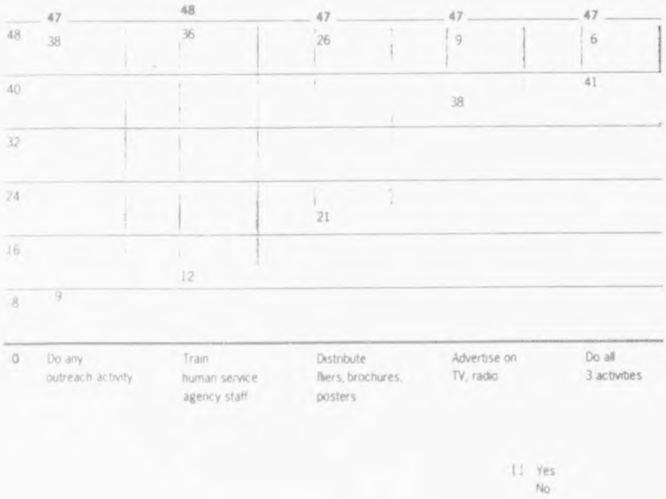
Many poor women do not qualify for Medicaid: The average income eligibility ceiling is just $5,000

Many poor women do not qualify for Medicaid. In 1986, the income ceiling for eligibility in virtually all states was well below the federal poverty level of $9,120 for a family of three in that year. The ceiling averaged about $5,200 for all states—56 percent of the poverty standard—and ranged from $1,416 in Alabama (16 percent of poverty) to $9,900 in California (109 percent). Twenty-one states set a limit that was 25–49 percent of the federal poverty standard; 20 set it at 50–74 percent of poverty; and eight set it at 75–99 percent. Only Alabama had a ceiling below 25 percent of poverty; and only California set a limit that was above the federal poverty standard.[70]

One of the thorniest problems in Medicaid eligibility for maternity case is the question of coverage of teenagers who live with their parents or parent. All but two states consider the parents' income rather than the pregnant teenager's in determining her eligibility for benefits. If the parents are not already eligible for Medicaid, the young pregnant woman may have to leave her parents' home and set up her own household in order to qualify for benefits. (In five states, adolescents who are dependents living in families that receive Medicaid are given their own Medicaid card.[71])

32 Many women may not be aware they qualify for Medicaid; only 6 states make aggressive efforts to inform them

Because Medicaid is generally administered by the welfare bureaucracy, it is not surprising that many states concentrate more on keeping ineligible applicants out of the system than on reaching out to make sure that all those who qualify are included. Efforts to inform pregnant women about the availability of Medicaid benefits and to help them through the application process are sparse and uneven. More than 80 percent of states do some kind of outreach; the most common activity is training staff in such human service agencies as welfare and health departments about Medicaid eligibility and benefits (75 percent of reporting states do so). Only a little over half distribute informational materials through human service agencies to tell clients about the availability of services, and just about one in five make use of TV or radio advertising. Only about one-eighth of all reporting states—six states—conduct all three types of outreach activities. Most Medicaid literature does not specifically indicate that pregnancy is a ground for eligibility. Even when it does, the information is sometimes out of date, and may discourage eligible women from applying.[12]



The Medicaid application process is slow and complex; only three states speed review of applications by pregnant women

The process of applying for Medicaid is complicated and may greatly delay the moment when women can begin their prenatal care. Eight percent of pregnant women covered by Medicaid don't start prenatal care until the third trimester; three percent get no care at all (compared to three percent and two percent, respectively, among all women who give birth).[73] Typically, pregnant women covered by Medicaid make 8.7 prenatal care visits, whereas the average expectant mother makes 10.5 visits.[74]

Once a woman finds out that she is pregnant and decides to apply for a Medicaid card, she must fill out an application form. In most states, this form is long and complex and requires extensive documentation. The filing of an application usually involves several visits to the welfare office. Forms average 14 pages in length and can run to as many as 40 pages. Only 11 states allow Medicaid workers to go to clinics to help applicants fill out these forms. Only three of 45 states for which there are data indicate that they process Medicaid applications in a week or less. In most states, a pregnant woman, like all other Medicaid applicants, must wait a month or more to receive the card that entitles her to subsidized services. Only three of 48 reporting states expedite the review process for a pregnant woman; the same number permit health care providers to give a pregnant woman a temporary Medicaid number.* All in all, only nine states—20 percent—take any of these steps to reduce delays in coverage for pregnant women.[75]

Under Medicaid, all states reimburse providers for one or more of eight specialized services or diagnostic tests performed during pregnancy.† Thirty-six—or 75 percent of states for which there are data—cover all eight. In some states, however, important services are not covered. Six states, for example, will not pay for an Rh immune globulin injection. Even within states, conditions for payment may vary. Thus, providers may be denied reimbursement for services they have already given, or patients may be denied services they need.[76] Despite these problems, once a pregnant woman surmounts the many obstacles required for certification, in most states Medicaid does cover most necessary services.

*Seven more states have taken advantage of a recent revision in the law allowing providers to serve pregnant women thought to be eligible for Medicaid and, pending determination of their eligibility, to claim reimbursement (see [illegible]

†Rh immune globulin, ultrasound, fetal oxytocin stress test, fetal nonstress test, amniocentesis, alpha fetoprotein screening, cytogenetic study of amniotic fluid and L/S ratio analysis.

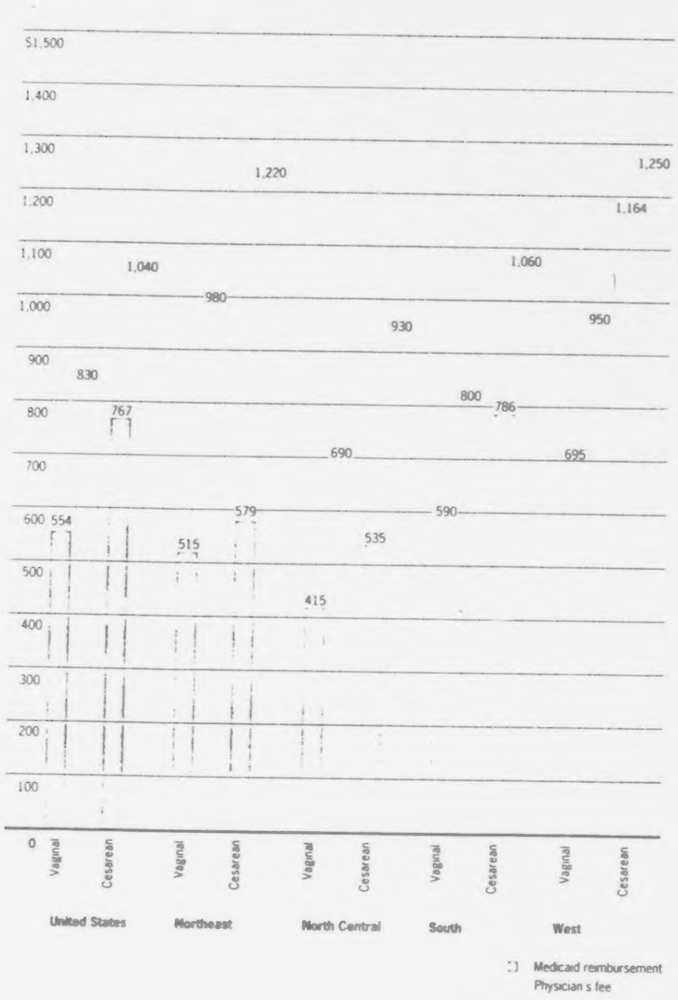
Four in 10 obstetricians will not accept Medicaid patients; reimbursements can be low, slow, complex and uncertain

Only 35 percent of women whose delivery is paid for by Medicaid go to a private physician for prenatal care, compared with 73 percent of all women and 83 percent of women who are not poor.[77] This difference is not surprising, since 44 percent of doctors providing obstetric services will not accept Medicaid payments for delivery.[78] Doctors are reluctant to accept Medicaid patients for a number of reasons. Perhaps one of the most important of these is that reimbursement rates—although they have risen substantially in recent years—are still below physicians' usual charges. In some states, they are strikingly lower.

In 1986, physician fees averaged $830 for a vaginal delivery and $1,040 for a cesarean section.[79] The maximum Medicaid reimbursement for a normal vaginal delivery averaged $554, but it ranged from as little as $216 in New Hampshire to $1,027 in Massachusetts. Florida limits the *total* payment for prenatal care alone to $62.50—less than one-tenth the average physicians' charge for prenatal care. The average nationwide reimbursement for a cesarean section is $767—ranging from $325 in New Hampshire to $1,303 in California.[80]

Total Medicaid payments for maternity care in 1985, including those for the physician and hospital (but excluding neonatal intensive care), averaged about $2,200; but these payments varied widely by state, from $1,310 in Louisiana to $3,520 in Tennessee,[81] and are about two-thirds of the comparable national average charge of $3,440 for such care.[82]

Factors other than low reimbursements make physicians reluctant to accept Medicaid patients: States sometimes stop making payments altogether if they run out of money before the end of the fiscal year; claims are often returned or rejected; it is the responsibility of health care providers to obtain, complete and file the Medicaid claim forms, which adds significantly to their paperwork burden; payment is often delayed until well after the delivery, forcing providers to wait many months for their money; and many providers fear malpractice suits when dealing with Medicaid patients, who tend to be at higher than usual risk of adverse outcomes.[83]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535
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415
Vaginal
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Cesarean
Vaginal
Cesarean
Vaginal
Cesarean
United States
Northeast
North Central
South
West
Medicaid reimbursement
Physician's fee

Special publicly funded clinics provide prenatal care to 660,000 poor women; 6 in 10 of them not insured

Poor women are disproportionately dependent on clinics—such as those operated by health departments, hospital outpatient facilities, and community and migrant health centers—for their prenatal care. This is especially true of women on Medicaid: Sixty percent of women whose delivery is subsidized by Medicaid, and 39 percent of poor women (that is, women with family incomes under 100 percent of the federal poverty standard), obtain their prenatal care at a clinic, compared with just 21 percent of all women.[84]

Two major public programs support clinics that provide maternity care primarily to poor women, some of whom have Medicaid coverage, but most of whom do not. One is the state-administered Maternal and Child Health (MCH) program, financed jointly by the federal government and the states, to provide health care to poor women and children.[*] The other is a federal program that supports more than 560 community and migrant health centers.[†][85] These two programs support a network of clinics that provide care in communities where it is not otherwise readily available. There are community and migrant health centers or MCH providers in every state except Wyoming, but the clinics are not necessarily available in all areas of need.

In 1986, an estimated 660,000 patients obtained prenatal care through these two programs—213,000 in community or migrant health centers and 447,000 in MCH clinics located mainly in state and county or city health departments.[‡][86] (Other publicly subsidized programs also provide some prenatal care. These include hospital clinics, university health centers and Indian Health Service clinics.)

About six in 10 states have set special Medicaid reimbursement rates for some types of clinics that reflect their provision of patient education, outreach and treatment to a high-risk population. However, only four in 10 states apply these rates to health departments, community health centers *and* MCH clinics.[87]

Fifty-seven percent of the prenatal care patients served in these two programs, or about 375,000 women, have neither public nor private health insurance. Another 32 percent are covered by Medicaid, and 11 percent have some private insurance, although they may not be covered for maternity care. Sixty-four percent of patients in these programs have family incomes that are below the federal poverty level; all but five percent have incomes below 200 percent of the poverty standard. In addition, a large proportion of patients are young. These are groups that are at high risk of pregnancy complications; 32 percent are teenagers, more than twice the national average.[88]

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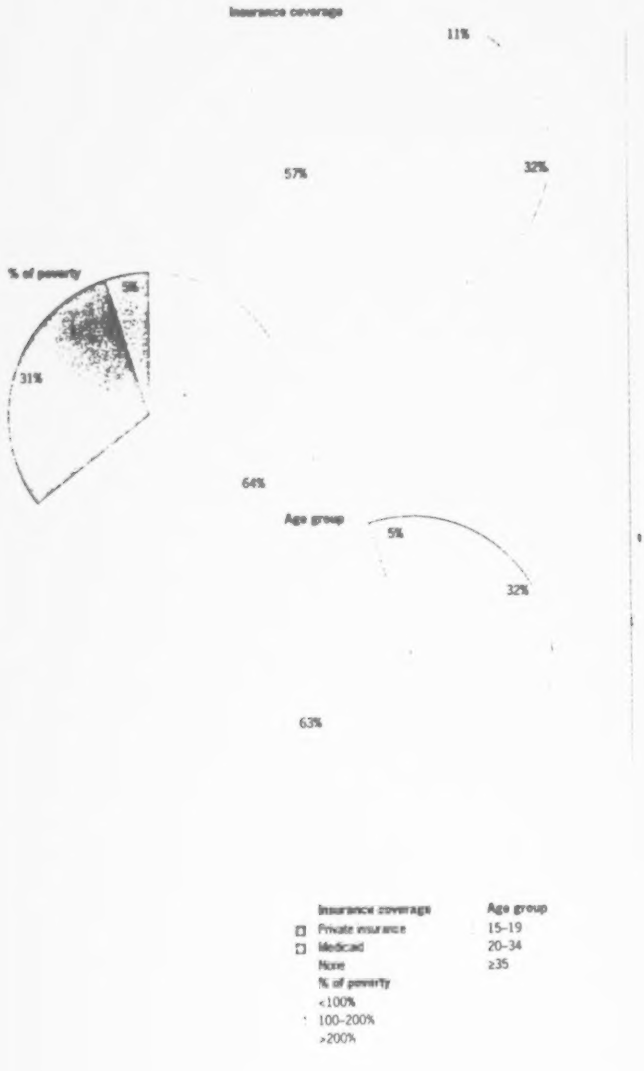
[*] *In April 1987, the AGI sent a questionnaire about maternity care financed with MCH funds to the director of the MCH division of the health agency for each state and the District of Columbia; all but three states [illegible] and the District of Columbia responded.*

[†] *In March 1987, the AGI sent a questionnaire to the executive director of each community and migrant health center. Approximately 76 percent of the [illegible] representative sample, according to region, urban-rural location and agency type.*

[‡] *There may be some, but we believe little, overlap of patients served through these two programs.*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32%
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32%
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Insurance coverage
Private insurance
Medicaid
None
% of poverty
<100%
100–200%
>200%
Age group
15–19
20–34
≥35

One-fifth of mothers get prenatal care through special clinics; most get no help with hospital bill

Nearly one in five of the 3.7 million women who give birth each year obtain prenatal care at MCH clinics or at community or migrant health centers—a total of 660,000 women. This proportion is much higher, however, for the subgroups at highest risk of pregnancy problems. Thus, four out of 10 of the half-million teenagers and of the one million poor women who give birth each year obtain their prenatal care at one of these types of clinics, as do one-third of the 630,000 women whose delivery is paid for by Medicaid and two-thirds of the 555,000 women who arrive for delivery at the hospital with no insurance.[89]

Although MCH programs and migrant and community health centers provide prenatal care for a substantial number of poor women, the connection between these programs and the hospitals where the delivery takes place is weak.[90] Only 16 states require MCH-supported clinics to make arrangements for hospital delivery for their patients, such as transfer of medical records. Sixteen states will not allow MCH funds to be used to pay the physician's fee for delivery.[91] Thirty-six percent of community and migrant health centers do not schedule or arrange for hospital admission for their prenatal patients; of these, 17 percent do not even transfer the woman's records to the hospital where she is to deliver. However, medical staff from the centers attend about half of the deliveries of their patients, and the centers pay for an outside physician to attend an additional 19 percent.[92]

Among the 660,000 women who obtained prenatal care through MCH-supported clinics or community or migrant health center programs in 1986, only a tiny proportion were helped by these programs to pay their hospital bills. Only six percent of women who got prenatal care in MCH-supported clinics, and just 3.5 percent of those who got care in migrant or community health centers, obtained such assistance; and there is almost certainly some duplication in these numbers. Moreover, even in the rare circumstances under which these programs do contribute, the payments are usually quite modest.[93]

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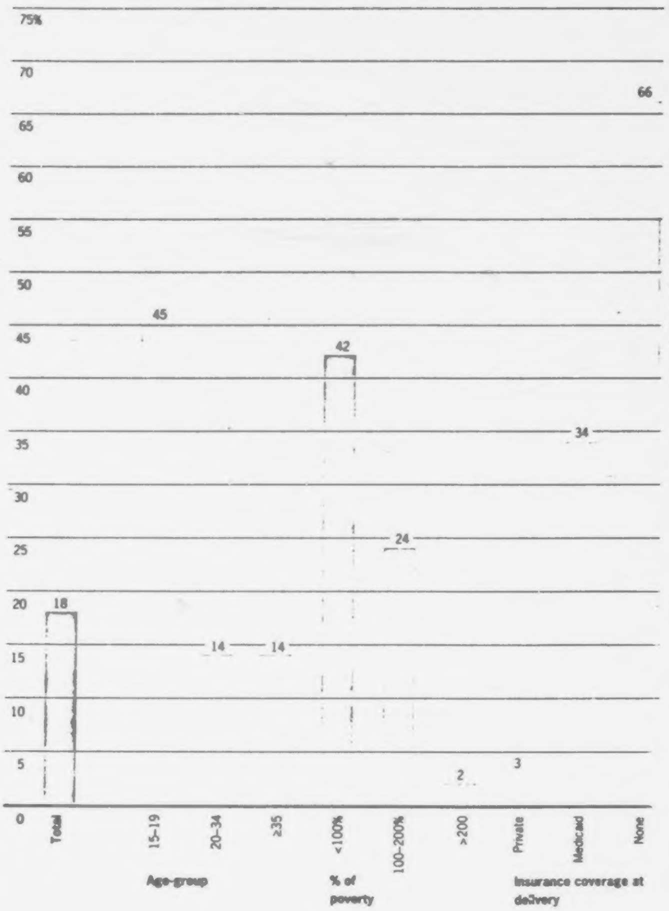

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States set wide range of limits on family income to determine eligibility for subsidized care in public clinics

MCH programs in four states (Alaska, Montana, North Dakota and Wyoming) do not provide prenatal care. In two states (Louisiana and Virginia), the programs will not serve women at high risk of adverse birth outcomes; in four states (Hawaii, Idaho, Minnesota and South Dakota), they serve only high-risk women. In addition, 15 percent of all community and migrant health centers do not offer prenatal care, and 34 percent that provide prenatal care will not serve patients at high risk of adverse outcomes, possibly because of the difficulty and high cost of obtaining malpractice insurance.[94]

Eligibility for free or subsidized care under the MCH program is generally based on family income, and the income limits vary considerably among states. Of the 39 states for which there are data, the largest number (21) set the maximum at 150–199 percent of the federal poverty standard (about $14,000–$18,500 for a family of three). Nine states set it at 250 percent or higher, or set no income restrictions; six set it at 200–249 percent of poverty; one uses 146 percent as the cutoff; and two adhere to the 100 percent level.[95]

Women Who Have No Insurance

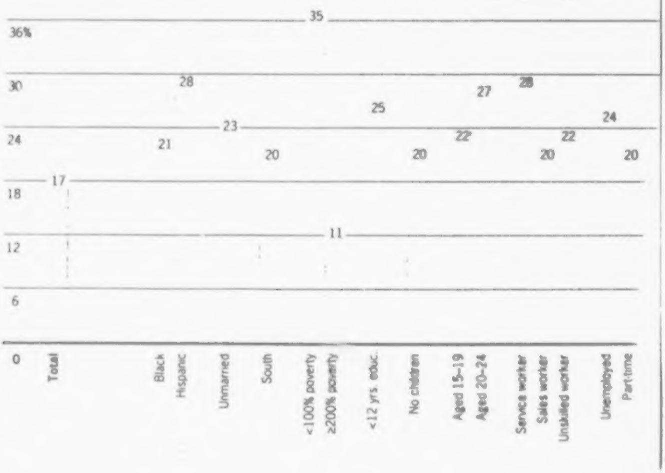
Young women employed in beginning or low-paying jobs often have no public or private health insurance

As noted earlier (see chart on page 20), 17 percent of women of reproductive age—about 9.5 million women—have no public or private health insurance. The proportion among poor women is more than twice as high (35 percent). Women who are Hispanic, have less than 12 years of education, work in service occupations or are in their early 20s are 50 percent more likely than the average to have no health insurance. Women who are black, unmarried, in their teens or who are unemployed are among other groups in which relatively high proportions have no coverage.

The reason that teenagers and women in their early 20s are more likely than average to be without insurance is partly that they are more often childless than are older women—and, therefore, are less likely to be eligible for Medicaid coverage—and partly that young people tend to be employed in beginning or low-paying jobs that do not offer insurance benefits. The percentage without coverage is highest among women who are both young *and* have family incomes below the poverty level—41 percent for poor women aged 20–24 and 40 percent for those aged 15–19.[96]

Because of the way in which private insuranc is tied in to the workplace, it is not surprising that a larger-than-average proportion of wome who are unemployed or employed part-time ar without insurance. In addition, women employe in certain occupations—for example, in the farming or service sector (or married women whose husbands are employed in those occupations)—are even less likely than the unemployed to be covered by insurance. This i probably because their employers do not provide a health insurance plan and their income is too high to make them eligible for government-subsidized programs.

Recent trends in patterns of employment make it likely that increasing proportions of women of childbearing age will be without health insurance. Since 1970, the proportion employed in industries with high levels of insurance coverage, most notably manufacturing and transportation, has been declining, whi the proportion employed in occupations least likely to have health insurance, in particular the service and retail sales sector, has been rising In addition, the proportion of women in their early 20s working part-time is on the increase.



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14.6 million women 15-44 have no insurance for maternity care; 555,000 new mothers have no coverage for the delivery

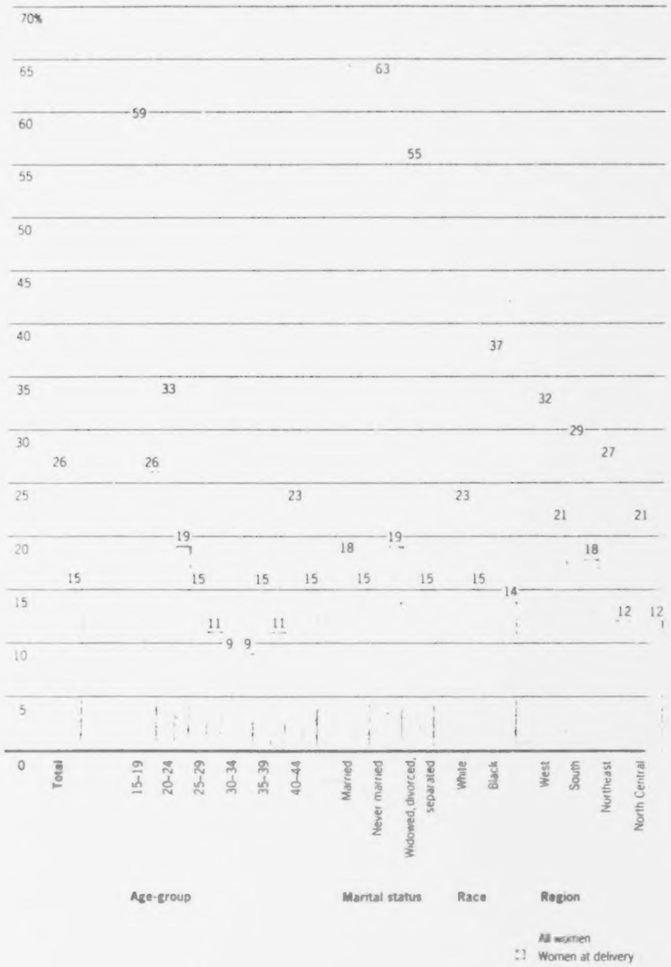
Twenty-six percent of women of reproductive age—14.6 million of them—have no insurance to cover maternity care. Seventeen percent have no insurance at all, and nine percent have private health insurance that does not cover maternity care.[98] Sixty-three percent of never-married women, 59 percent of teenagers, 55 percent of those who are widowed, separated or divorced and 33 percent of those in their early 20s have no health insurance that covers maternity care. The percentage is higher among nonwhites than whites (37 percent vs. 23 percent) and among women from the West than from other regions of the country.[99]

Many poor and near-poor women are without any health insurance coverage: 3.2 million women of reproductive age with incomes below the poverty line and another 2.8 million with only marginal incomes ($9,300 and $13,900, respectively, for a family of three) have no health insurance coverage.[100]

By the time they actually give birth, the proportion uninsured is reduced from 26 percent to 15 percent. That is because many poor women become eligible for Medicaid only after a pregnancy is diagnosed. However, even at the time of delivery, some 555,000 women each year are not covered by any kind of health insurance.[101]

By the time of delivery, Medicaid coverage has eliminated the gap between whites and blacks of reproductive age who have no coverage for maternity care. Nevertheless, teenage mothers and those in their early 20s remain much more likely than older mothers to be without insurance for delivery. Never-married mothers and those from the West and the South also remain relatively more likely to be uninsured.

Among the 15 percent of mothers who arrive at the hospital for delivery with no insurance coverage, 10 percent have had no prenatal care or they obtained it only in the third trimester. The proportion having obtained late care is twice as high as the national average, and the proportion who have gotten no care is about four times the national average.[102]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West
South
Northeast
North Central
Age-group
Marital status
Race
Region
All women
Women at delivery

Maternity and newborn care represent 27 percent of $7.4 billion in annual unpaid hospital bills

Care that is not paid for by either insurance or the patient—commonly called uncompensated care—amounted to $7.4 billion in 1985. Of this total, $1.1 billion was covered by state and local tax appropriations, $1.7 billion was allocated by hospital budgets for charity care, and $4.6 billion represented uncollectable bills.[103] The amount of uncompensated care continues to rise, and must be absorbed by hospitals, taxpayers or higher health insurance premiums for the insured and their employers.

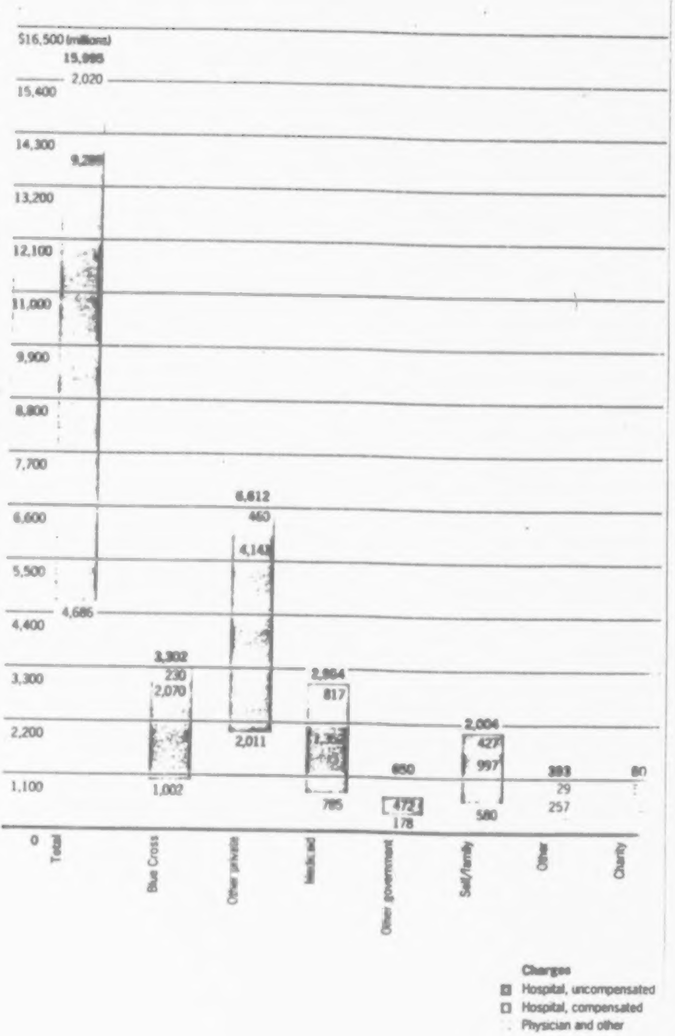
Some 60–75 percent of uncompensated care is generated by patients who have no health insurance, and the rest represents costs beyond the amount covered by insurance that the patient does not or cannot pay.[104] Although maternity patients are more likely than other hospitalized patients to pay their bills, maternity and newborn care is nonetheless the biggest single source of uncompensated care: In 1981, obstetrics patients accounted for 45 percent of all hospital patients who received uncompensated care and for 28 percent of all uncompensated care charges.[105] A study conducted in 1982–1983 in Vanderbilt University Hospital found that care of newborns accounted for almost half of all unpaid bills of more than $25,000, and the average unpaid charges for newborns came to $6,185.[106] Studies conducted during the 1980s in South Carolina, Tennessee, Texas and Virginia produced similar findings.[107]

Currently, about 27 percent of the $7.4 billion in uncompensated hospital care is accounted for by unpaid bills for maternity care—an estimated $2.0 billion of the $16.0 billion spent for maternity care in 1985. This estimate of uncompensated charges for hospital care includes $57 million generated by charity patients, $817 million from bills of Medicaid patients for services not reimbursed by Medicaid, $690 million from bills unpaid when there is insufficient private insurance, $427 million that is unpaid when the patient is billed directly and $29 million from bills unpaid by coverage from other sources.[108]

In the past, private hospitals often sought to shield themselves from the risk of unpaid bills by refusing to admit indigent patients who had no insurance. Congress has recently authorized penalties for physicians and institutions that turn away women in active labor,[109] but the law does nothing to prevent them from refusing care to women who are in the early stages of labor—a nice distinction that is more appropriately made in a textbook than in an emergency room—or who have pregnancy complications. In a survey of state directors of maternal and child health taken shortly after the law went into effect, all but 14 said some hospitals in their states turn maternity patients away, and 13 said that some hospitals deny admission to women not yet in active labor.[110]

Women who have no health insurance may also be asked to pay a preadmission deposit. At least some hospitals in eight out of 10 states surveyed by the AGI in 1987 require a deposit averaging about $510 from uninsured maternity patients.[111] Forty-eight percent of community and migrant health centers reported that at least one hospital in their community requires such a deposit, generally between $500 and $1,000. Although about half of the agencies have successfully negotiated agreements whereby their patients may be admitted without paying a deposit, virtually all said that at least some patients have to be admitted on an emergency basis.[112] In such instances, the physician who assists with delivery usually does not know the patient or her problems and has no medical records for guidance.

Charges for [illegible] care, by whether hospital care was compensated or uncompensated, according to source of payment, 1985



4. Conclusions and Recommendations

The United States is one of the few industrialized countries that does not have a universal health financing system that guarantees uniform basic medical care to all who need it. Health care in the United States is, however, heavily subsidized by the federal government. Indirect subsidy is provided through tax rebates to employers who insure their employees and through tax deductions for individuals whose medical expenses reach certain levels. Direct government subsidies are provided through such programs as Medicare for the elderly and the guaranteed health benefit programs for dependents of members of the armed forces, and for veterans and their dependents. Finally, the federal government provides over half the money for the state-administered Medicaid programs.

An individual's health insurance coverage at any given time depends on such changing factors as employment status, type of work, state of residence, family structure and income and assets, age, disability and even the existence of a particular medical condition, such as end-stage renal disease.

Under such a patchwork system, it is not surprising that certain individuals and groups are disproportionately without any health insurance. The number of uninsured people is rising. Some of the reasons for that increase are the growth of employment in low-paid service and sales areas with few fringe benefits, continued high unemployment among young people and minorities, increased part-time employment and the high cost of insurance. The last of these is the result of a disproportionate inflation in medical expenditures due to the development of sophisticated medical technologies and the sharp increase in malpractice insurance premiums.

At the same time, tighter federal and state budgets have curtailed government health benefits and services, resulting in pressure on physicians and hospitals to accept lower reimbursement for services rendered to Medicare and Medicaid patients. Escalating medical costs have caused private employers to limit the benefits offered to their employees. Employers have also become increasingly resistant to paying higher premiums and the hidden surcharges on hospital bills that have traditionally been used to cover the cost of care to the uninsured. Many hospitals and medical practitioners have taken to selectively accepting insured patients, whose bills are most likely to be paid, and discouraging or even turning away others.

These problems have prompted discussions at all levels of government and within the private sector about how to obtain more uniform and comprehensive health insurance coverage for everyone. Some improvements are already evident. For example, in 1986, Congress enacted legislation to end the frequent automatic loss of health insurance coverage for individuals who terminated employment, whose insured spouse died, who became divorced or separated from the insured person, or who passed the maximum age allowed for dependent coverage. Under the new law, these persons can continue participation in the existing group plan at their own expense for a period of 18 months to three years. These new provisions should offer substantial protection against the sudden loss of insurance coverage for those who can afford it. Additional legislation has been introduced in Congress that would require all employers to provide basic insurance coverage to their employees and that would expand public financing for those currently ineligible for employment-related coverage. Immediate, far-reaching, truly national reform, however, seems unlikely at this time.

Improving Maternity Care Financing

As this publication has shown, women having babies in the United States typically have low or modest incomes, primarily because they are young and starting out in the work force. Therefore, they are more likely than other groups in our society to be without health insurance or to have inadequate coverage. Although most pregnant women receive some prenatal care, and virtually all deliver their babies in a hospital, there is abundant evidence that late, discontinuous medical supervision during pregnancy and uncertainty about childbirth arrangements are distressingly common. The Congress and state legislatures have in the past few years demonstrated special concern that adequate prenatal and maternity care be available for all those who need it. This concern may have followed the realization that investment in the health of women during pregnancy and childbirth is a prudent and relatively low-cost commitment to the future well-being of children, families and society as a whole.

In 1978, the Congress passed the Pregnancy Discrimination Act to end the common practice among private health insurers of excluding maternity benefits from the policies they issue. This law requires most employment-related group health insurance and other health benefit programs to cover pregnancy-related medical care (except abortion) in the same manner as they cover all other kinds of medical care. As a result, most—but, as we have seen, not all—women covered by group health policies are now covered for maternity care.

In 1986, Congress broadened Medicaid eligibility requirements for pregnant women and effectively severed the connection between their eligibility for Medicaid and their eligibility for welfare payments under the Aid to Families with Dependent Children (AFDC) program. Under AFDC, welfare assistance is given to needy children and their adult caretakers according to income standards established by each state. In most states, benefits are limited to unmarried mothers and the children living with them. The Medicaid program was created in 1965 to provide medical care for these same families. The Congress, in creating a new category of eligible persons—pregnant women—based solely on financial need and on nationally set income criteria, has made a radical departure from traditional concepts and laws.

As a result of this congressional action, states are permitted, though not required, to provide Medicaid coverage for pregnant women and young children who may have family incomes up to the federally established poverty standard ($9,300 for a family of three in 1987). The Congress may further extend the maximum allowable income limit—perhaps to the level permitted for the Special Supplemental Food Program for Women, Infants and Children (185 percent of the poverty standard, about $17,200 for a family of three). If it does, the federal government will continue to assume at least half of the cost. However, Medicaid expenditures are a large, and a steadily growing, component of many state budgets, and state governments face considerable public pressure to keep down the costs of what is widely viewed as a "welfare" program.

It is improbable, therefore, that all states will rapidly and uniformly expand coverage, and the ones least likely to be able to do so are poor states where the need is most acute. Even states that take advantage of the new option may be reluctant to embark on aggressive efforts to inform pregnant women of the expanded eligibility requirements, enroll them quickly and generally facilitate their participation. Finally, if they increase maternity care expenditures for Medicaid and, thereby, relieve the burden of uncompensated care carried by insurers and hospitals, states may be tempted to reduce other expenditures for community-based programs, education and outreach targeted at high-risk groups of women and children.

Furthermore, changes in eligibility alone—or even implementation of suggestions that uninsured persons who cannot afford private insurance be allowed to "buy into" Medicaid—will not have much effect unless major changes are also made in the way the Medicaid program works. In particular, states may have to be given incentives to encourage people to apply for Medicaid rather than seek to deter such applications. For example, poor but employed individuals may well be discouraged from applying because they cannot easily make several visits to the local welfare office during working hours to establish eligibility. To decrease the number of women without medical coverage, states will have to make vigorous efforts to inform people that they are eligible for Medicaid and to simplify, speed up and humanize the application process.

To encourage women to seek early prenatal care and to stimulate health care providers to offer services, Congress recently revised the Medicaid law so that states could give local health care providers authority to serve pregnant women thought to be eligible and, pending a determination of their eligibility, to claim Medicaid reimbursement. As of mid-1987, however, only seven states had taken advantage of this option.[113] In addition, as we have seen, many health care providers, especially physicians in private practice, are unwilling to accept Medicaid patients. This situation is not likely to change so long as Medicaid reimbursements are low, slow and uncertain, and so long as the paperwork remains voluminous and complex.

Finally, despite the exception that Congress has made to the traditional linkage between receipt of Medicaid benefits and welfare payments, Medicaid retains its image as a program for welfare recipients. This linkage profoundly affects and perpetuates the way in which Medicaid is administered, the negative way it is viewed by the public and the stigma those who might benefit from its expansion generally attach to the receipt of welfare-related benefits.

Next Steps

The major steps taken by Congress and some states to extend insurance coverage and services to pregnant women and their children are encouraging. But they need to be carefully and continuously monitored, since changes in the law are rarely self-executing. Certain measures could also be taken to alleviate some of the obvious difficulties in existing insurance coverage. These include the following:

- Require coverage for maternity care of all women insured under private policies, whether purchased individually or as part of a group, and coverage for all newborns from the moment of birth. Make certain that spouses and nonspouse dependents are covered in all employment-related policies.
- Establish uniform coverage of all necessary physician and hospital services for the pregnant woman and her newborn, including physician care of well babies in the hospital.
- Waive waiting periods and restrictions on coverage of preexisting medical conditions for all care related to pregnancy and childbirth.
- Gradually expand the Medicaid program to cover maternity and newborn care for those who cannot purchase private health insurance, with premiums graduated on the basis of a family's ability to pay.
- Require states, or at least provide financial incentives to them, to make aggressive efforts to inform poor women about the availability of Medicaid subsidy for maternity care.
- Mandate or give financial incentives to states to process Medicaid applications from pregnant women within a reasonable period of time—say two weeks from the first contact.
- Establish state systems not linked with the welfare system to handle Medicaid applications.
- Give states incentives to offer health care providers reasonable reimbursement for maternity and newborn care and to reimburse providers at periodic intervals during pregnancy, if the provider wishes to bill periodically.
- Encourage states to reimburse adequately all clinics that provide prenatal care services (including nutritional, educational and outreach services) to Medicaid-eligible women.
- Expand educational programs aimed at reducing unplanned pregnancies, especially among teenagers, and increase the availability of free or low-cost family planning services.
- Strengthen community-based services, such as are provided in MCH-supported clinics and community and migrant health centers, and improve their connections to the hospital where the delivery will occur to assure continuity of care. (These types of services will continue to be needed by poor women at high risk of adverse birth outcomes even if all are eventually covered by health insurance.)
- Educate employers and insurers about how inclusion of prenatal care in insurance benefits actually saves money that would otherwise be spent for treatment of complications suffered by infants whose mothers did not get proper preventive care.
- Expand research that examines the impact of current medical practices on pregnancy and delivery.
- Improve coordination among the various public programs providing or financing prenatal care and between the providers of prenatal care and the providers of delivery services.
- Finally, address through legislation the problems created when hospitals turn away patients with pregnancy complications or who are in the early stages of labor.

An Alternative Approach

Implementation of the recommendations made here would improve the current patchwork system of coverage for maternity and infant care and would help relieve financial pressure on consumers, providers, employers and insurers. It is doubtful, however, that all of the suggestions will be adopted, that they will be adopted by all states or that they will be adopted within a reasonable period of time. If the goal is to make certain that all women of reproductive age and their families have insurance coverage for at least basic prenatal, maternity and infant care, an alternative approach would be to provide such coverage through a uniform nationwide system. Such a system would be less cumbersome and expensive to administer than the many different systems currently employed. It would eliminate the state-by-state variations in eligibility and benefits inherent in the Medicaid program, and also circumvent the stigma attached to programs designed and administered with only welfare clients in mind. As has been shown repeatedly in this document, most of the expenses of maternity and infant care are already being paid by somebody—if not by private insurance or Medicaid, then eventually by the public, through inflated premiums, taxes or charity. The only "new" expenses of a nationwide system would be for early prenatal care. However, these expenditures are relatively small and would undoubtedly save money in the long run by improving the health of new mothers and newborns. Such a universal system could be financed through a combination of public and private revenues and be administered under the auspices of the federal government, as are Medicare and Social Security. It would provide a basic, uniform benefit package with built-in cost control provisions, and would cover all pregnant women and their babies, regardless of family income.

Dollars Not All

There is less-than perfect agreement about what maternity care services are optimum or necessary and under what circumstances they need to be provided. Controversies about the relative value of different interventions have led to confusion among providers and insurers, and to inconsistent coverage of various services and procedures by both public and private insurers. Understandably, as these affect both quality and cost of care, this ambiguity about what *should* be provided is of great concern to employers, insurers and taxpayers. Professional groups and institutions representing physicians and hospitals may achieve consensus on some of these issues, but consumers and payers are often left out of the process. (Such representation is missing, for example, from the expert panel convened by the Public Health Service to formulate recommendations on the content and efficacy of prenatal care.) One final recommendation, therefore, seems appropriate and even essential to obtain the kind of working national consensus that is needed:

- The president or the Congress should convene a commission, including representatives of medical organizations that set standards, public and private insurers, employers, consumers and providers of maternity care, to define the content and reasonable costs of a basic maternity and newborn care package that all payers should cover.

In conclusion, it must be acknowledged that removing financial barriers alone will not ensure that all pregnant women obtain optimum maternity care. There will probably always be some women who, for a variety of reasons, fail to get care promptly or regularly or to make adequate prior arrangements for hospital admission. (For them, special outreach, recruitment and tracking will need to be devised and carefully evaluated.) There will probably also be some health care providers who provide less-than-adequate care or who refuse to serve poor people. Furthermore, we can expect that for some time to come, there will be geographically uneven distribution of medical services. And, for a long time to come, we must anticipate the need for a strong, comprehensive network of community services to meet the special needs of disadvantaged groups.

Adequate and effective financing would not solve all the problems we now face, but it would help—considerably. What is more, such a financing system would probably cost society as a whole no more (though it would redistribute those costs) than does the patchwork of inadequate and inconsistent programs and policies that now finance maternity care in the United States. Certainly, it is unconscionable that we as a society appear to care so little for the next generation that we cause couples to hesitate about having a baby for fear they can't afford proper medical care, and place obstacles in the way of pregnant women who seek and need such care.

nachri

ROBERT H. SWEENEY
President

May 31, 1988

The Honorable John Chafee
U.S. Senate
Washington, D.C. 20510

Dear Senator Chafee:

Because of the limitation on time during the Finance Committee's hearing on "Health Care for Seriously Ill Children," I did not have an opportunity to respond to your question about your bill, S. 1537, the "Care Management and Catastrophic Health Care Act." I want to take this opportunity in writing to state again the strong support of the National Association of Children's Hospitals and Related Institutions for this legislation and for your leadership in bringing Congress to address the health care needs of children. I plan to ask the Finance Committee to include this letter in its hearing record.

In these fiscally constricted times, the Congress has not found the budgetary means to undertake the type of major initiative S. 1537 represents for children and their families. But, it is clear to us that this legislation and your persistent efforts on behalf of it, already have had an important effect. Today, unlike a year ago, members of the Finance Committee are talking about catastrophic coverage as a children's issue, not just a problem facing the elderly. And today, unlike any time in recent years, members of the committee are talking about the need to ensure universal access to health care for all children.

We think such a change in outlook is vital to building the political will and momentum that will be needed for serious action on the kind of change in health care coverage for children that S. 1537 as well as your MedAmerica proposal represent. We look forward to continuing to work with you to advance health care coverage for all children.

Sincerely,

Alexander R. White, Jr.
Chief Executive
Santa Rosa Children's Hospital
San Antonio, Texas

The National Association of Children's Hospitals and Related Institutions, Inc.
401 Wythe Street, Alexandria, Virginia 22314
Phone (703) 684-1355

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ROBERT H. SWEENEY
President

June 17, 1988

The Honorable Lloyd Bentsen
Chairman
Committee on Finance
U.S. Senate
Washington, D.C. 20510

RE: Submission for the Record of the May 26 Hearing on the "Health Care Needs of Seriously Ill Children"

Dear Senator Bentsen:

I would like to submit for the record of your May 26 Finance Committee hearing on the "Health Care Needs of Seriously Ill Children" this letter in comment on the General Accounting Office Study of Chronically Ill Children, which is now underway.

NACHRI supports this study, requested by the Committee. We have had extensive conservations with GAO about it, and 13 children's hospitals are participating in GAO's surveys and interviews at our encouragement.

As the Committee reviews the preliminary results of the GAO study, as described in the GAO testimony for this hearing, members will want to keep in mind two points:

- The study focuses on 10 specific conditions of chronic illness, identified by a 1985 Vanderbilt University study of childhood studies. It is important for the Committee to recognize that these 10 conditions are not inclusive of all children's chronic illnesses, particularly of the high cost conditions. For example, Children's Hospital Medical Center in Cincinnati found that in preparing data on the particular illnesses requested by GAO, the addition on two additional categories of cases for "extreme immaturity" and "pre-term infant NEC" increased by almost 50 percent the total patient days and hospital

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charges attributable to all of the conditions GAO is studying. In just the three years since the Vanderbilt study, we are seeing a growing number of cases of children surviving, with technological support and high cost care, as chronically ill or disabled children. A complete picture of chronic illness needs to take them into account.

- The preliminary results of the GAO study identify two problems involving lack of access to social services such as foster care and respite care needed by the families of chronically ill or disabled children released from the hospital. These problems are a lack of case management or coordination and a lack of financing. Our hospitals' experience, which includes case management, suggests that the problem is less one of insufficient case management and more a problem of the services simply being unavailable. The point is: case management alone, without the resources to establish and sustain needed social services, can have only minimal effect. This is particularly true in rural areas, where both medical services and social services often are lacking for the seriously chronically ill or disabled child.

In conclusion, I would like to commend you and your committee for the seriousness and thoroughness of your attention to the many problems standing in the way of comprehensive health care coverage for all children.

Sincerely,

Robert H Sweeney

Robert H. Sweeney
President

RHS/mrw
cc: Marsha Andrasik, Association of Ohio Children's Hospitals

nachri

ROBERT H. SWEENEY
President

June 17, 1988

The Honorable Lloyd M. Bentsen
Chairman
Committee on Finance
United States Senate
Washington, D.C. 20510

RE: Statement for the Record
of the May 24 Hearing on
"The Status of Primary
Health Care for Children"

Dear Mr. Chairman:

On behalf of the nearly 100 institutions that are members of the National Association of Children's Hospitals and Related Institutions (NACHRI), I commend the Committee for conducting its series of hearings on the subject of child health. We particularly appreciate your examination of the status of primary health care for children on May 24, and request that this letter be added to the hearing record, along with the testimony we presented in the May 26 hearing on the health care needs of seriously ill children.

Many children -- most of them poor -- rely on the emergency rooms and outpatient departments of children's hospitals as regular sources of primary care. As major providers of primary as well as acute care, our hospitals know first-hand both the experience of impoverished families seeking primary health care for their children and the consequences for children's health when primary care is not accessible.

- Medicaid Providers Children's hospitals are largely urban hospitals whose missions are to serve not only very sick children, but also very poor children. On average, children's hospitals provide more than a third of their care to low income children, and more than a quarter to children covered by Medicaid. Compared to general hospitals, children's hospitals provide three times the volume of services to Medicaid patients. As a consequence, children's hospitals are major providers of primary care as well as acute care. For example, in 1985, a children's acute care hospital on average reported about 83,000 outpatient and emergency department visits while a general acute care hospital on average reported less than half that amount, about 38,000 visits.

The experience of Children's Hospital of Michigan in Detroit illustrates how children's hospitals are large providers of primary care to poor children. For example, the hospital's

Emergency Department sees an average of 60,000 patients per year; close to 60 percent of those children are seen for primary care. Fifty-eight percent of E.R. visits involve either Medicaid patients for whom reimbursement is inadequate or self-pay patients who do not reimburse the hospital.

Children's of Michigan also has a large ambulatory pediatric service that provides primary as well as specialty care. The service has about 12,000 primary care visits per year. Sixty-two percent of the ambulatory care service's primary care is to Medicaid patients, and 12 percent is to direct-pay patients for whom the hospital is not reimbursed.

- Primary Care Providers Children's hospitals witness the results of the lack of primary care among poor children, particularly in terms of preventable diseases. Between 1981 and 1985, for example, pertussis or "whooping cough" increased from approximately 1250 to 3275 cases nationwide. Children's hospitals are particularly likely to see these cases -- over half of the children required hospitalization and of them, one in five suffered complications of pneumonia. The majority of cases were preventable if these children had received adequate immunizations, a key element of primary care.

Primary Health Care Definition |

Primary care for children refers to a variety of preventive health services that include ambulatory care, prevention and treatment of acute diseases and disabilities, and management of common chronic disorders. The primary care services that our hospitals deliver include: immunization; well-child health supervision that consists of physical examinations and other tests that screen for illness or developmental problems; episodic care for self-limiting illnesses and injuries; post-hospitalization follow-up care; and health education and parental guidance.

Barriers to Access to Primary Care

Most primary care services delivered by children's hospitals are to poor and uninsured children who are not able to obtain such services from private physicians. Poor children are three times as likely to use a hospital outpatient department or emergency room as their regular source of care. Because of our hospitals' experience in being the only regular source of primary health care for such children, we know the barriers their families encounter in seeking primary care and providers encounter in trying to make it available:

- Inadequate Insurance and Medicaid Coverage - Access to care is a major problem for many children who lack a "medical home" where they can receive regular, comprehensive, quality primary care. According to the American Academy of Pediatrics, an estimated seven million children in the U.S. currently receive no medical care.

  Key to that lack of access is inadequate insurance coverage to finance care. One out of every five children -- about 11 million children -- has no health insurance. In 1986, about 40 percent of uninsured children had no physician visits in spite of the need for regular period health assessments and immunizations.

Children of poor and working poor families are especially vulnerable. Two-thirds of uninsured children are low income; 40 percent are below the federal poverty level. Medicaid today serves 400,000 fewer children than a decade ago -- despite a 30 percent growth in child poverty. Not surprisingly, poor children are twice as likely to have no regular source of health care.

Furthermore, while it is of great benefit to those children who are eligible for it, Medicaid coverage of primary care continues to vary dramatically among states. For example, according to one 1987 report, Idaho's Medicaid program covered only four well-child screening visits from birth through age 21, and Oklahoma and Wyoming covered only five as compared to Ohio, Pennsylvania, and Washington, which covered 25 visits. In contrast, the American Academy of Pediatrics recommends a total of 20 such visits. Thus, children of low income families will continue to lack the "medical home" and adequate visits they need for quality primary care as long as Medicaid discrepancies in eligibility and scope of coverage persist.

- Inadequate Physician Reimbursement - Physicians who care for children on Medicaid encounter severe restrictions on the reimbursement they receive. Generally, Medicaid fees are well below those paid by Medicare and private insurance, and the disparities are growing. Between 1982 and 1984, private physicians' fees increased 13 percent while the median Medicaid reimbursement remained unchanged. Several states have not raised fees for primary care services since the early 1970s. In many states, Medicaid reimburses physicians and hospitals far below their cost of doing business. Stringent Medicaid reimbursement discourages physicians' participation in Medicaid which, in turn, hinders children's access to necessary health care. Bureaucratic red tape and payment delays also discourage providers from participating in the program.

  Such payment and administrative barriers make it difficult for families eligible for Medicaid to obtain primary care for their children from physicians in private practice. Children's hospitals have witnessed a trend toward greater reliance of these children on hospital emergency and outpatient departments as their "medical homes" for primary care. While children's hospitals persevere in their mission to provide care to poor children, the fact remains that children who rely upon emergency and outpatient departments for their regular source of primary care face more substantial barriers to receiving care and experience less continuity in the care they receive.

- Inadequate Disproportionate Share Adjustment - For children whose access to primary care is impeded by financial barriers, children's hospitals become the source of primary care and treatment for disorders or disabilities that could have been prevented or detected earlier. Since children's hospitals often are located in low income communities, they frequently serve a "disproportionate share" of poor patients who cannot pay or for whom Medicaid payments do not cover hospital costs. While all states are now required to begin offering increased payments for inpatient services provided by hospitals that serve a disproportionate share of the poor and uninsured, almost none will do so for outpatient care. As a result, children's hospitals place themselves at financial risk as they continue to deliver primary care to Medicaid and other low income children.

Recommendations

There are several steps the Committee can take to address the primary health care needs of poor children.

1) The Committee can continue its efforts to expand Medicaid eligibility for low income children, moving beyond infants with incomes below the federal poverty level to all children.

2) The Committee can move to establish uniform, minimum primary health care services covered by Medicaid for all eligible children.

3) The Committee should explore the need to expand the recently enacted federal mandate for disproportionate share adjustments for inpatient services in every state Medicaid plan to outpatient and primary care services.

4) The Committee should explore other incentives and demonstration grant programs for low cost, primary care services -- in school and community settings -- that reach low income families.

In the long run, however, the Committee needs to take on the larger problem of inadequate health care coverage of children -- whether they be children of poor families unable to obtain even primary care or children of more affluent families for whom catastrophic coverage is unavailable.

The children's hospitals are especially encouraged by the interest of Committee members expressed in your hearings in taking a comprehensive look at children's health care needs. Children's hospitals would be pleased to assist you and your colleagues in any way we can.

Sincerely,

Robert H. Sweeney
President

LARRY B. SILVER, M.D.

Mr. Chairman and distinguished Senators, I am Larry B. Silver, M.D. and I am honored to appear before you on behalf of the American Psychiatric Association, a medical specialty society representing more than 34,000 physicians nationwide, and the American Academy of Child and Adolescent Psychiatry, a national professional association of over 3,900 Child and Adolescent Psychiatrists. Currently, I serve as Director of the TRI-Services National Institute of Dyslexia and Clinical Professor of Psychiatry at the Georgetown University School of Medicine. Prior to assuming my current positions, I served in other academic positions and in a number of capacities at the National Institute of Mental Health, including Acting Director. I am well-acquainted with the issues of delivery of appropriate mental health services to all areas of our childhood population and have a particular expertise in developmental disabilities.

While children with mental health problems are covered by a wide range of Federally-funded programs, coverage varies and access to the services may be impeded due to lack of coordination or cooperation among agencies. In addition, coverage of mental disorders in private insurance programs is limited and rarely equivalent to coverage of other physical illness. With coverage limited in both the private and pubblic sectors, costs for care of children with mental disorders can easily become catastrophic. My testimony today focuses on estimates of the number of children with mental disorders, current available funding for children with mental disorders and options for addressing future needs. The testimony is not focusing on the area of drug abuse among today's youth, although it is a problem of which we are all well aware.

Numerous Presidential Commissions and private commissions since the beginning of this century have specifically dealt with the need for new programs for mentally disturbed children including the first White House Conference on Children (1909), the Joint Commission on Mental Health of Children (1975), the Project on the Classification of Exceptional Children (1975), The Presidential Commission on Mental

Health and its Task Force on Infants, Children, and Adolescents (1978), Select Panel for the Promotion of Child Health (1981), Knitzer/Children's Defense Fund Survey of State Mental Health Programs (1981, 1982). All of these reports continue to point to the dearth of well-coordinated services provided to mentally ill children and the need for more available services for this population. Coordination of service delivery is a particular problem because of the overlay and overlapping responsibilities of the health care system, the educational system and the social welfare system.

Estimates of the Number of Children With Mental Health Problems

Estimates of the number of children under 18 years of age who have mental health problems at any one time range from 5% to 15% of the population. The Congressional Office of Technology Assessment's December 1986 background paper on Children's Mental Health: Problems and Services estimated that between 12 percent and 15 percent or between 7.5 million and 9.5 million of the approximately 63 million U.S. children under the age of 18 suffer from mental disorders that warrant intervention, but that less than one percent of these children receive treatment in a hospital or residential treatment facility, approximately 5 percent and 2 million children receive outpatient mental health treatment.

In addition to children who have diagnosable mental disorders, certain environmental risk factors such as poverty, divorce, substance abusing parents, and child physical and sexual abuse and neglect may place children at risk and require preventive early intervention. Identification of children's psychiatric disorders is much more difficult than with adults. Although there is to date limited good research on children's mental health problems and on the effectiveness of treatment interventions, the Congressional Office of Technology Assessment (OTA) concluded that "...treatment is better than no treatment and that there is substantial evidence for the effectiveness of many specific treatments."

As the OTA noted in its report, numerous studies have estimated the number of children with mental disorders, however, the exact numbers within the population who need mental health services have not been adequately determined and may, in fact, be underestimated. Appropriate studies of the prevalence of these disorders still need to be conducted, and it is hoped that studies such as the NIMH Epidemiologic Catchment Area Study will soon provide more accurate data. Even though there is a tendency to avoid labelling of children as chronically mentally ill, there are certain childhood disorders that tend to be chronic in nature. These disorders include: pervasive developmental disorders, childhood schizophrenia, schizophrenia of adult type manifesting in adolescence, severe behavioral disorders requiring long-term residential care, mental retardation and other developmental disabilities with accompanying mental disorders. Since no precise definition of "chronic mental Illness in children" exists, in my own research, using Delphi techniques, I estimate the numbers of children with these most severe disorders to be approximately one percent or half a million individuals.

Federal Funding of Service Delivery to children with mental disorders

The major Federal programs affecting the delivery of mental health services to children include: the Alcohol, Drug Abuse and Mental Health (ADM) block grant program, third party payment programs such as Medicaid, Medicare and CHAMPUS (Civilian Health and Medical Program of the Uniformed Services); mental health services provided under the Education for All Handicapped Children Act (PL 94-142); and the modest CASSP (Child Adolescent Service System Program) funded through the National Institute of Mental Health (NIMH).

The proportion of expenditures specifically for children's mental health needs through these programs is difficult to determine, but one study of State Mental Health Agencies (SMHAs) conducted by the National Association of State Mental Health Program Directors found in 1983 that

7% or $9 per capita was spent on childrens mental health services versus 45% or $22 per capita on adult mental health services.

Under the ADM block grant (PL 97-035), funds are provided to the states for provision of mental health services. The proportion of these funds specifically allocated for children is not known because the block grant is segmented with specific funds for alcohol, drug abuse, and mental health programs, and the percentage of block grant funds allocated to mental health services differs among the States. It is also unknown which of the three categories of programs has specifically allocated funds for childrens services. In addition, although the original Community Mental Health Centers Act of 1963 required these centers to specifically report on funds spent on children, this reporting mechanism is no longer specifically required. The 1985 ADM block grant however did require a 10 percent set aside for childrens' services. This entire set aside may however be no more than 20 million dollars nationwide--not a great deal of money to meet the extensive needs of the child population.

In 1985 Medicaid served 11 million dependent children under the age of 21, but the amount of mental health services provided to this group is unknown. A GAO report on this issue is scheduled to be released by the end of the year and may shed further light . While the actual amount of mental health services provided to Medicaid eligible children is unknown, the Medicaid program provides coverage for a wide variety of mental health services. Through coverage of SSI (Supplemental Security Income) related children, Medicaid is a significant payer of institutional care. Mandatory Medicaid services include: inpatient hospitalization, outpatient hospital services including day treatment and other forms of partial hospitalization, physicians (including psychiatrists) services, and Early and Periodic, Screening, Diagnosis and Treatment program services (EPSDT). Optional services include: prescription drugs, case management, clinic services (including community mental health psychologists and social worker services, inpatient psychiatric facilities, intermediate care facilities for the mentally retarded and developmentally disabled (ICF/MR,DD), and other home and community-based services approved through the waiver program. An expansion of eligibility under Medicaid in 1984 did not specifically require mental health services or assessment for children, but a 1986 provision did allow for case management so that children could have access to needed services may prove beneficial to mentally ill children. The low financial eligibility overall, wide variations in eligibility criteria and the extent of coverage among the states limit the potential of Medicaid as a payer of services. Although more than half of the states offer potentially unlimited coverage of many mental health services, some states provide as little as $450 per year or as few as 12 visits for outpatient services.

The importance of the EPSDT program which allows states to cover services not included in the state plan or to increase the amount, duration, or scope of services provided to children cannot be overstated. However, the inherent flexibility of the EPSDT benefit is not being utilized as well as it could be for all children, and particularly for mentally ill children. Only 20 states (Alaska, Arkansas, Connecticut, Delaware, District of Columbia, Florida, Hawaii, Illinois, Kansas, Kentucky, Maryland, New Jersey, New York, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, Wisconsin) provide for expanded coverage under EPSDT. While all states are in compliance with the Federal mandate to require a developmental assessment as part of EPSDT screening examinations, only seven states (Alabama, Delaware, Louisiana, Michigan, South Dakota, Utah and Vermont) require any specific screening for psychiatric and psychological problems. The choice of the developmental assessment tool is left to the states.

The Medicaid 2176 home and community-based waiver program, under which states may greatly expand home care to individuals in lieu of institutionalization, has been utilized very effectively for mentally retarded children, but remains greatly underutilized for children with mental and other physical illness. There are widespread reports of state reluctance to request waivers because of the very burdensome administration requirements. Currently, only one state (Vermont) administers a program providing home and community-based services to mentally ill children.

Decreasing institutionalization and shrinking state mental health outpatient resources have resulted in a greater reliance upon the special education system as a provider of care to emotionally disturbed children. The Education for all Handicapped Act (PL 94-142) provides a free appropriate education and related services for all handicapped children. The Federal government provides a small amount of money for the program but mental health services are not always considered related services. Mental health service provision under PL 94-142 has been very uneven. The new early intervention program (Part H of PL 99-457) offers great promise for the creation of a statewide, coordinated interagency system of comprehensive early intervention services for children age birth to three who are experiencing a developmental delay, have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay, and at the state's discretion, are "at risk" of substantial delay. While psychological services were enumerated among the covered services in the statute, physicians are not specifically mentioned as providers. Psychiatric services may therefore be greatly limited or precluded altogether in the "birth to three" programs as they may be in special education in general. For the early intervention program, education is the last payer, preceded by Medicaid and other public payers. The broader financial base and the eligibility criteria for the birth to three programs are very welcome. However, transitional problems may occur when the children turn three years of age and enter the existing special education system where education is the sole payer and children "at risk", but not clearly manifesting learning problems, are not usually served.

Other issues regarding provision of services to the children with mental disorders under the Medicaid program include unclear regulations in certain areas and managed care issues. Medicaid HMO enrollment offers the benefits of managed care to children who have special medical needs and mitigates the problems of low Medicaid reimbursemnet rates and subsequent low rates of provider participation. At the same time, HMO mental health benefits (which are typically 30 inpatient days per annum and 20 outpatient visits per annum) may be too low to serve severely emotionally disturbed children. In fact, anecdotal evidence has suggested that the more severely mentally ill person in an HMO setting has not always received appropriate care. This may be pariticularly significant for the SSI-related Medicaid population which by definition, is seriously ill.

Current regulations are also unclear as to whether residential treatment centers, skilled nursing facility level Institutions for Mental Disease, group homes and other supervised living situations accredited by Joint Commission on Accreditation of health organizations (JCAHO) may be covered as Medicaid service. This lack of clarity hinders placement of children in the most appropriate setting.

Medicare covers some (but very few) mentally disabled children but bears special importance because many states have adopted Medicare rules for payment. CHAMPUS provides a wide range of services for children, but in recent years has cut back on some of these services. As mentioned previously, coordination of services is always a problem, but for children with severe chronic problems the State Comprehensive Mental Health Services Act of 1986 and the modest Child and Adolescent Service System Program (CASSP) funded through NIMH may assist in coordination. Both of these programs are relatively new and their full impact cannot yet be evaluated. One program in North Carolina (initiated after a 1979 lawsuit) has provided a complete community-based continnum of care for seven years for severely emotionally disturbed and assaultive minors. In a presentation at the 1987 annual meeting of the American Academy of Child and Adolescent Psychiatry, Behar and Kayve indicated that the North Carolina program recognized important essentials including, but not limited to, the fact that with a continuum of services the mental health needs of the severely disturbed population can be met, these severely disturbed children use multiple services at one time and therefore need to be part of more than one system. Even these programs, however,do not yet address the needs of coordination of services for those children who are not yet severe or chronic.

Future

Despite childrens' extensive needs for mental health and other health services the current systems of health and mental health care have many gaps. APA hopes the Congress will continue to address very carefully service and coverage needs of our children. Prevention of mental disorders and appropriate coverage is absolutely essential. These services must be available on a continuum of care and must not place the child in the position of falling through the cracks of the educational, health and welfare systems.

Statement of

Mark E. Swanson, M.D.

Mr. Chairman and Members of the Committee:

I am Dr. Mark Swanson, Director of the University Affiliated Center, in Dallas, Texas, which is a part of the University of Texas. Thank you for giving me the opportunity to testify today on the health care needs of children with chronic illnesses.

OVERALL COORDINATION OF CHILD HEALTH SERVICE DELIVERY

Although my brief remarks will address a number of specific issues, the single most significant point I want to make today is this: the lack of coordination among state and local administering agencies, service providers and third party payers is one of the primary barriers to the provision of health care not only to chronically ill and technology dependent children, but to children as a whole and of all ages. Services for mothers and children are traditionally dispersed among various State agencies with, in many cases, overlapping and contradictory mandates and responsibilities. Agencies will often deny services based upon their determination that responsibility for services is located in another organization. Interpretation of agency policies is in many instances inconsistent, resulting in differing availability of services. This organizational structure yields programs serving children without the appropriate coordination and, as a result, hampers access to appropriate care.

According to a recent report to Congress on technology dependent children, parents -- particularly those of children with special health care needs -- are faced with the task of first, identifying available programs in their area and second, successfully navigating the maze of programs in order to assemble a complex package of services for their child. Some parents are successful in this process. Many others, however, are frustrated by their inability to identify appropriate services, overcome bureaucratic roadblocks in obtaining identified services, and managing a multiplicity of providers, services and third-party payers. Clearly, Mr. Chairman, the primary focus of federal policy-making in this area must be to promote collaboration between -- on the one hand -- the providers of medical, educational and social services and --on the other hand-- public and private funding agencies.

Recently, a group of major organizations representing professionals, child health advocates and state agencies gathered to develop a comprehensive legislative approach to the problems I have just described. This joint proposal, which is still in the drafting stage, attempts to bring cohesion to our existing maternal and child service delivery system at the two levels where it counts the most. It would, of necessity, involve significant changes to the Maternal and Child Health Block Grant funded under Title V of the Social Security Act.

First, the recommendation would mandate the development of a state-wide maternal and child health service delivery plan, which entails the establishment of clearly defined objectives and the identification of both unmet health care needs and underserved populations. Unlike the existing system, the planning process would explicitly involve the most important providers, consumers, and insurers in a given state including professionals, the state Medicaid agencies, parents, federally funded nutrition programs and voluntary advocacy groups among others. The principal purpose behind this joint exercise is to establish a single, cohesive approach to child health care issues. A properly developed plan would have, as its principal components, the identification of serious state-wide problems (such as low birth weight and associated infant mortality, for example), the establishment or modification of service delivery systems to address those difficulties and --most importantly-- the coordination of limited resources to insure that the necessary service provision is properly funded.

Second, on the level of the individual child, the group endorses a coordinated, family centered care coordination initiative -- to be administered by the Title V Programs for Children With Special Health Care Needs -- for children who incur significant medical or health care expenses in a given year. A plan, developed on an individual basis, would specify the type of care required and identify both the providers and resources available to pursue agreed upon health and developmental objectives. Note that nothing in the group's proposal would result in the dimunition of vital services currently furnished through Title V. On behalf of the American Association of University Affiliated Programs, I strongly support these proposals and urge your swift consideration and approval once they are formally submitted.

TECHNOLOGY DEPENDENT CHILDREN

Mr. Chairman, the same issues I just described affect the two populations of children with chronic illness that I wish to spend the remainder of my time here discussing: technology dependent children and handicapped infants and toddlers between birth and three years old.

In recent years, certain federal and state programs have attempted to facilitate the transfer of children requiring ventilator and similar high technology from tertiary health care centers and hospitals to community and home-based settings. This policy shift resulted from research which revealed dramatic improvements in the health and developmental status of chronically ill and handicapped children who remained at home. Without going into considerable detail, the enhanced personal attention and family involvement available in community-based programs produced substantial gains in physical and cognitive development, speech development, psycho-social development and self-help skills. In short, these children have longer life expectancies and make greater progress in overcoming the functional limitations associated with chronic illness and developmental disabilities. Consequently, there is an increased likelihood that they will live independently and remain outside of large congregate institutions.

However, the maintenance of a technology dependent child in a home or community-based environment requires the development of a considerable support system. For example, a series of in-home multidisciplinary services should be provided including physical therapy, speech-language pathology, occupational therapy, nutritional consultations and the services of a social worker among other requirements. In a foster home, specialized training for foster parents in a host of areas is critical. Moreover, physical modifications to the home itself are often necessary along with the arrangements required to mainstream the child into a regular classroom.

The University Affiliated Center in Dallas is addressing these issues at several levels. At Children's Medical Center, an infant education team has been organized with hospital and University Affiliated Center personnel to facilitate the transition of technology-dependent children from the hospital to the community. Specifically, we are training both hospital personnel and community service providers in the realities of life outside the medical center for medically complex children and their families. In addition, the UAC will provide technical assistance and training to the Texas Chronically Ill and (CIDC) Disabled Children's Bureau, as it has been charged with providing coordinated care to 200 technology-dependent children in Texas awaiting transfer from hospital to home.

In collaboration with Texas CIDC, the UAC will be setting standards for coordinated care management by (1) a demonstration project for sickle cell children in rural East Texas and by (2) assessing the quality of care management in other CIDC-funded demonstration projects.

But significant barriers exist to the community integration of these children. Prime among them is the institutional bias of Medicaid policy, which often makes it difficult for providers to receive reimbursement for services rendered in the community. Many states fail to cover vital care coordination services. The fragmented child health service delivery system I described earlier is also a significant problem.

In general, Congress did not intend Title V to address these broad policy questions. However, through the federal set-aside, it did provide the MCH Block Grant with the legislative mandate to deal with another significant impediment to the transfer of technology dependent children into home and community-based programs: the preparation of personnel. In order to maintain a child requiring a ventilator or similar high technology in the home, it is essential that allied health professionals schooled in the multidisciplinary process be available to furnish appropriate services. Consistent with the need to foster an interdisciplinary, interagency approach for each child and family to assure successful community integration, the Bureau of Maternal and Child Health must provide a focused, coherent, multi-year training program for community health care, education and related services personnel.

And make no mistake, Mr. Chairman, the requirement for such a program is growing with the number of technology-dependent children in need of services. Using a fairly narrow definition, the Office of Technology Assessment recently estimated that there were 17,000 such children across the United States. The increasing number of children with complex medical and technological needs is actually a national success story. It results from both rapidly advancing medical technology and the enhanced skills of providers. As a result, it is incumbent upon federal and state policy makers to keep pace with needed training and service programs that will allow these children to reach their maximum potential in the most appropriate, least restrictive environment.

HANDICAPPED INFANTS AND TODDLERS

Similar considerations apply in examining the service requirements of handicapped infants and toddlers between birth and three years old. Indeed, the recent legislative approach to the health and developmental needs of these children could serve as a model for service provision to all chronically ill youngsters. The 1986 amendments to the Education of the Handicapped Act, Public Law 99-457, assists states to develop and implement a comprehensive, coordinated, interdisciplinary program of early intervention services for infants who are "at risk" of a developmental disability. In that legislation, Congress addressed many of the issues I've talked about today including state-level cooperative planning, interagency coordination and multidisciplinary service provision.

Specifically, in order to receive federal assistance, the states must appoint a lead agency that is responsible for both the promulgation of a state-wide service delivery plan and coordination of payments for intervention services from various public and private sources. Recognizing that interagency cooperation is instrumental in meeting the service needs of handicapped infants, Congress required the states to appoint an Interagency Coordinating Council (much like the advisory board currently being proposed by child health groups) to assist in policy development. In addition, under Part H of the law, a series of multidisciplinary services are required including speech pathology and audiology, physical and occupational therapy, case management services, family training and early identification, screening and assessment services among several others.

The impact of this legislation has been enormous. In Texas, it is estimated that 34,000 children 0-3 years old have an established developmental delay or a significant biologic risk for delay. In 1987-88, the state-funded Texas Early Childhood Intervention Program served 10,175 children. With the addition of new federal dollars, under the Education of the Handicapped Act, Texas will still be unlikely to have the financial resources to serve even the most high risk infants. And even with adequate finances, Texas has inadequate numbers of trained personnel to serve the population. For the past 6 years, the UAC has conducted personnel development institutes to provide interdisciplinary training in developmental disabilities for early intervention service providers, many of whom had no other formal training whatsoever.

You may ask, why should amendments to be an education law be relevant to maternal and child health care? First and foremost, many of the infants served under P.L. 99-457 will end up on the service roles of the Title V Programs for Children with Special Health Care Needs because of the early identification and assessment services called for under the law combined with the proven success of early intervention services as a whole. In fact, many states have appointed their health departments as the required lead agencies under legislation.

In turn, the Bureau of Maternal and Child Health has recognized this reality by furnishing representatives for a Federal Interagency Coordination Council that has as one of its primary objectives facilitating the implementation of the new EHA amendments. In the view of my Association, Mr. Chairman, the MCH Block Grant has a critical role to play in this arena. Once again, recent data reveal that personnel preparation is a major obstacle to the provision of early intervention services to our Nation's handicapped infants and toddlers. As an illustration, a recent study of 44,000 occupational therapists nationwide indicates that fewer than 2% have EVER provided treatment to children between birth and three years of age. Moreover, a survey of the 50 states and territories completed in 1987 establishes that 82% have reported significant shortages of the physical therapists and speech-language pathologists necessary to implement P.L. 99-457. In fact, the State of Massachusetts recently cited personnel training as the number one barrier to implementation of the legislation.

Federal and state agencies responsible for training allied health professionals cannot stand idly by in face of these staggering numbers. A coordinated, highly focused approach to this issue is clearly necessary. Specifically, we propose a personnel development initiative -- administered through BMCH -- designed to assist States in planning and implementing professional and paraprofessional health-related, in-service training programs to facilitate the provision of early intervention services. Health-related technical assistance to the key state planning and administrative bodies established under P.L. 99-457 including the Interagency Coordinating Councils, the lead agencies and the Regional Resource Centers is also a critical component of this initiative.

In conclusion, Mr. Chairman, thank you for allowing me the opportunity to speak out on these vital issues.

Statement of

Alexander R. White, Jr.

Mr. Chairman and members of the committee, I am Alexander R. White, Jr., chief executive officer of Santa Rosa Children's Hospital, a 192 bed facility which is part of the Santa Rosa Health Care Corporation in San Antonio, Texas. I also am immediate past president of the Children's Hospital Association of Texas, which represents five children's hospitals throughout the state. In addition, before joining Santa Rosa last year, I served as the executive director of Texas Children's Hospital in Houston.

I appreciate the opportunity to appear before you today on behalf of NACHRI -- the National Association of Children's Hospitals and Related Institutions -- of which I am a former member of the Board of Trustees. The American Hospital Association joins us in supporting the recommendations contained in our testimony and will submit its own detailed recommendations for the record.

NACHRI is the only national, voluntary association of children's hospitals. It represents nearly 100 institutions, including 6 hospitals in Texas. Virtually all of NACHRI's members are teaching hospitals and involved in conducting research. Most are also regional medical centers receiving referrals from larger geographic regions in the U.S. and from around the world. In my testimony, I will describe: 1) children's hospitals' missions of care; 2) children's hospitals' special experience with children with chronic conditions; 3) chronic illness and catastrophic illness expense in children's hospitals; and 4) NACHRI's recommendations for Congressional action.

Children's Hospitals' Missions of Care

Children's hospitals have missions of providing care for very sick children, children with special health care needs, and children of low income families, particularly those eligible for Medicaid and those for whom no public or private coverage is available.

Very Sick Children Children's hospitals are perhaps best known for the care they provide to children with severe health problems. According to our analysis of 1986 data from a sample of children's hospitals and general hospitals, the nature of the illnesses treated by children's hospitals results in average lengths of stay about 50 percent longer than in general hospitals. The intensity of the care patients require in children's hospitals results in average charges per patient nearly three times as great. The volume of care involving children with extremely long stays or high costs of care (outliers) is about twice as great. And an overall measure of case mix intensity is about two times as great. NACHRI estimates that more than 27 percent of the beds in children's hospitals are devoted to intensive and special care. More than 40 percent of children's hospital patient care involves infants; health care costs of children in the first year of life are often the most expensive.

Children with Special Health Care Needs Children's hospitals around the country have established reputations for having developed centers of highly specialized services. For example, Texas Children's in Houston as well as Children's Hospital in Boston are major centers of care for pediatric heart patients. Children's Hospital of New Jersey in Newark, Children's Hospital National Medical Center in D.C., and Los Angeles Children's Hospital all have become leading centers of care for children with HIV infection. Children's Hospital of Pittsburgh and Children's Medical Center of Dallas are important centers of expertise for organ transplants. Children's Hospital Medical Center of Akron is a center for treatment of children with severe burns. These specialized centers are an important reason why children's hospitals provide care to children far from home.

Very Poor Children Perhaps less visible than their commitments to the care of very sick children and children with special health care needs, but equally essential, is the mission of many children's hospitals to serve children of low income families who reside in the urban communities in which these hospitals often are located. More than a third of the care children's hospitals provide involves children of families who either depend on government assistance for health care coverage or are without any insurance entirely. More than a quarter of children's hospital care on average specifically involves children covered by Medicaid -- three times the volume of care on average that general hospitals provide. In my own hospital, more than 45 percent of Santa Rosa's patient days are devoted to caring for children under Medicaid. That is in a state in which a family must earn less than 26 percent of the federal poverty level to be eligible for Medicaid, that is, less than $2,200 for a family of three.

Because of their role as major providers of care to children in poverty, children's hospitals are acutely aware of the limitations to available public funding for health care. For example, Medicaid is the single largest payer of care in children's hospitals. Yet, on average nationwide, it repays the children's hospitals only 77 cents for each dollar the hospitals spend to care for children. As a result, Medicaid shortfalls account for about half of the uncompensated care of children's hospitals. It forces them to devote substantial portions of their charitable contributions and resources to subsidizing Medicaid rather than further expanding services to children lacking both public and private insurance.

Children's Hospitals and Chronic Illness

As a growing body of research and witnesses before this committee already have demonstrated, compared with other children, children with chronic illness or disability tend to be more frequently sick; more often in need of specialized health care; more likely to have families with low incomes; and more likely to depend on publicly funded coverage.

Given this profile, it is not surprising that children's hospitals are major providers of care to children with health conditions such as asthma, cystic fibrosis, leukemia, sickle cell disease, congenital heart disease, and others resulting in hospitalizations for more than one month per year or interference with a child's normal daily activities for more than 3 months a year. Children's hospitals often see these children first when they are acutely ill. Because they have developed programs of specialized care, they continue to care for these children, often into their adulthood.

Children with chronic illness and disability are frequently seen in children's hospitals. A study of 1983 data from 11 children's hospitals suggests that chronic health conditions accounted for more than 20 percent of all inpatient stays. Another analysis of 1986 data points to the greater volume of care children's hospitals provide to children with chronic conditions than do general hospitals. On average, the children's hospitals provided care for more than 10 times the proportion of cases of children with leukemia, 7 times for cystic fibrosis, 4 times for bronchopulmonary dysplasia (BPD). Similarly, children's hospitals are at the center of care delivery for the newest of severe chronic health conditions among children -- AIDS or HIV infection. A survey last fall of 19 children's hospitals indicated that they were seeing more cases of AIDS among children than the U.S. Centers of Disease Control reported nationwide.

Thus, many of the centers of specialized care in children's hospitals are devoted to specific chronic health conditions among children. Indeed, most have special programs of care for children with asthma, cystic fibrosis, and other respiratory problems. Children's hospitals are committed to the best possible care in the most appropriate setting: inpatient services, ambulatory specialty clinics, and home care programs. More than 20 children's hospitals already have established successful home care programs.

Children's Hospitals, Chronic Illness and Catastrophic Illness Expense

Today's hearing is devoted to children with chronic illness and children with high cost care. In children's hospitals, the unique care needs of children with chronic conditions are a special challenge in themselves. But they also are part of a larger problem, which children's hospitals have attempted to highlight during the past year -- the lack of consistent protection for families against catastrophic illness expense for children.

Catastrophic illness expense is relative -- one family's catastrophe may not tax another's resources. In our view, the need for catastrophic coverage exists wherever the financing of children's health care jeopardizes the financial survival of the family -- for a low income family, that could be even routine health care costs. In a case requiring the most sophisticated hospital treatment, expenses in the hundreds of thousands of dollars could threaten even an affluent family.

Children's hospitals see both ends of the catastrophic spectrum -- in their outpatient services which average two times the volume of general hospitals and in their inpatient care. A study of 1986 data suggests that compared to general hospitals, children's hospitals on average had more than 5 times the proportion of patient stays with adjusted charges of $50,000 or more. These high cost patient stays for children's hospitals also accounted for about 2.5 times the proportion of patient days that general hospitals had, and more than 2 times the percentage of total adjusted charges. In 1983, 1.35 percent of children admitted to children's hospitals had expenses exceeding $50,000, but they accounted for 26 percent of the hospitals' total inpatient charges. More than half were newborn infants. Catastrophic stays in children's hospitals in 1983-84 averaged 87 days and more than $100,000 in charges. Even with insurance few families, indeed, have resources adequate to meet such expense. Medicaid pays for about 24 percent of the catastrophic stays in children's hospitals.

While the care of children with chronic health conditions does not always result in such substantial expenses, it is often the case in children's hospitals. For example, according to 1986 data from children's hospitals, on average the care of a child for one hospitalization of acute leukemia with complications cost about $16,170; the care of a child for one episode of cystic fibrosis, about $10,450; the care of a child with BPD, about $10,300. And such children have repeated hospitalizations. In contrast, the average charge per patient stay for all patients in these same hospitals was about $6,680. When the data are examined in terms of length of stay and incidence of outliers the same pattern emerges -- they substantially exceed the hospitals' average experience.

The combination of children with catastrophic health care expenses, who are disproportionately from families of limited resources, means that public funding is critical to chronically ill children's immediate access to health care and the hospitals' long term ability to fulfill their missions of care. As I noted earlier, on average nationwide, NACHRI estimates that Medicaid reimburses children's hospitals for approximately 77 percent of their expenses. A separate study by the Children's Hospital Association of Texas shows how severe the problem can be at the state level. During 1986-87, Medicaid in Texas paid for about 40 to 50 percent of children's hospitals' charges; about 20 to 30 percent of intensive care nursery charges. As a hospital which accepts all patients regardless of their ability to pay, Santa Rosa's is especially affected.

Inadequate Medicaid reimbursement is a consequence of the different types of limits each state as well as the federal government places on Medicaid coverage. For example, in Texas the state's 30 day Medicaid reimbursement limit falls far short of the 87 day average for catastrophic cases in children's hospitals, the 56 day average for children requiring bone marrow transplants, or the 50 day average for extremely premature infants. In Santa Rosa's, 90 percent of our uncompensated care in 1986-87 -- about $2.8 million -- was the direct result of Medicaid patients whose stays exceeded the 30 day limit. Similarly, the state's $50,000 cap on Medicaid reimbursement falls far short of costs of the most extremely chronically ill, such as ventilator dependent infants whose hospitalizations can run $350,000 annually.

While Texas' limits are stringent -- there are no exceptions to them -- they are by no means unique. Based on a survey of state Medicaid agencies this winter, NACHRI estimates that about half of the states have strict limits on either number of days of inpatient care for which reimbursement is made or the total prospective payment per case. These are limits to which virtually no exceptions are made. For example, Alabama limits reimbursement to 12 days, with an extra 12 following a 2 week break; Florida, 45 days; Kentucky, 14; Mississippi, 30; Oregon, 18; Tennessee 20; and West Virginia, 25.

Such limits are not the only Medicaid obstacle to adequate coverage for children with chronic health conditions. For example, only a handful of states currently provide home and community based waivers on Medicaid coverage. Nor is private coverage free of problems. Limitations on pre-existing conditions and maximums on coverage are increasingly common among private insurance and employer-provided health benefits. And for an estimated 11 million children, the total absence of any insurance coverage, however limited, is an enormous problem. About 34 percent of children with chronic conditions lack any coverage. Among children with severe chronic conditions, about 37 percent lack coverage, according to 1984 data reported by the National Centers for Health Statistics.

NACHRI has lent its voice to specific proposals for Congressional action in 1988 and beyond to address the needs of poor children, children of the working poor, and children with special health care problems such as chronic conditions, plus the need of all children for catastrophic coverage. For 1989, we have focused on improvements in Medicaid coverage. For 1988 and beyond, we urge Congress to address a combination of public and private coverage proposals.

1988 Recommendations

- Congress should continue its efforts to expand Medicaid eligibility for children by mandating eligibility for pregnant women and infants living on incomes below the federal poverty level. According to CBO estimates, the annual cost of full year implementation would be less than $100 million to the federal government in FY 1989; less than $10 million for fourth quarter implementation. Provision of such resources would facilitate early treatment intervention and reduce chronicity.
- Congress should require every state to make exceptions to its Medicaid day and payment limits policies in cases of medically necessary inpatient care for infants in hospitals with a disproportionate share of Medicaid patients according to federal definition. CBO estimates full year implementation in FY 1989 would cost $12 million for exceptions to day limits; less than $2 million for fourth quarter implementation.
- Congress should expand coverage for home and transition care by either mandating home and community based waivers, which now are a state option, or increasing the matching rate for such care. In addition, Congress should direct HCFA to streamline the process for states to apply for waivers, and should encourage uniformity of coverage among states. Budget estimates are not available.

Long Run Recommendations

- Congress should undertake Medicaid reform on behalf of all children: mandated, uniform eligibility; expanded coverage; adequate reimbursement to ensure access to care; and care coordination. At a minimum, such reforms should include presumptive eligibility for infants, disproportionate share adjustements for outpatient services, enhanced "medically needy" programs, and improved teaching adjustments.

- Congress should initiate federal catastrophic insurance coverage of last resort for children to fill in coverage gaps, when all other resources are exhausted.
- Congress should explore tax policies to reduce limitations on private coverage's pre-existing conditions and to establish more realistic caps on life-time maximums.
- Congress should explore tax and/or mandate policies to expand employer-paid coverage for dependents.
- Congress should explore tax and/or mandate policies to encourage state risk pools and Medicaid buy-ins for the uninsurable.

Thank you very much for the opportunity to present our views. I would be glad to try to answer any questions you may have.

COMMUNICATIONS

STATEMENT OF
THE AMERICAN DENTAL ASSOCIATION
TO THE
COMMITTEE ON FINANCE
UNITED STATES SENATE

MAY 24, 1988

The American Dental Association appreciates this opportunity to present its views on child health care issues.

Over the last quarter century, the dental health status of the nation's children has improved to a level unprecedented in our history. By 1980, over 36 percent of American children were entirely caries-free, as compared to 28 percent with no decay in the early 1970's. A recent survey by the National Institute of Dental Research found that now half the schoolchildren in the United States have never experienced this dental disease.

This remarkable advance is directly attributable to dental research, in which the United States is the world leader; public health initiatives, most importantly the fluoridation of community water supplies; emphasis on preventive health measures in dental education, and intensified orientation toward prevention by practicing dentists.

Still, these continuing successes in protecting the dental health of children must not obscure the very real dental needs of certain child populations. Notably, children of economically disadvantaged families remain at increased risk of dental disease. Children in families with incomes below $5,000 visit the dentist half as frequently on average as those in families with incomes over $25,000. The National Health Interview Survey, conducted by the National Center for Health Statistics in 1981, disclosed that the percentage of economically disadvantaged children who have never seen a dentist is more than double that of the child population generally.

Since 1967, the principal means of providing dental care to the nation's economically disadvantaged children has been through Medicaid's Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program. Federal regulations require State Medicaid Plans to furnish to Medicaid-eligible children all dental care, at as early an age as necessary, which is needed for the relief of pain and infections, restoration of teeth and maintenance of dental health. The EPSDT Program nationwide has contributed measurably to improvement in the oral health status of Medicaid-eligible children over the last two decades. Its success, however, has been limited by disparties from state to state in the scope of dental services included in the Programs, in periodicity schedules, in systems to inform families of the availability of services and to assist with scheduling and transportation, and in levels of payment to dentists for services provided.

Moreover, Medicaid eligibility requirements are such that, on a national basis, less than half the population with incomes below the federal poverty line qualify for Medicaid coverage, including EPSDT services. According to the Association's 1987 Survey of Dental Programs in Medicaid, 18 states do not include the medically indigent in their eligible populations. Initiatives to improve the dental health of impoverished children should begin with a restructuring of the Medicaid program to provide uniform eligibility for all children in families with incomes below the federal poverty standard and to provide a minimum uniform set of dental services, comprising diagnostic procedures (dental examination, medical history and appropriate radiographs;) preventive services, (prophylaxis, topical fluoride application, pit and fissure sealants and space maintainers;) emergency services, restorative treatment, including periodontic, prosthodontic and endodontic procedures; oral surgery and pathology, and orthodontic care.

While the Association believes the dental care needs of categorically and medically indigent children should be given priority consideration in public dental health policy planning, the opportunities for further improvements in children's dental health generally must not be overlooked. The absolute eradication of dental caries in children is no longer merely an optimum goal toward which dentistry advances, but a reasonable, achievable objective. It is heartening to note that the size of the target population, beyond the economically disadvantaged population, is shrinking. Currently, it is estimated, 80 percent of carious teeth in children are found in 20 percent of the U.S. child population.

As we have discussed, poverty is one principal factor in defining this population. Physical and mental handicaps are another.

The Association, through close liaison with the American Academy of Pediatric Dentistry, the National Foundation of Dentistry for the Handicapped, and other involved organizations, seeks to address the special dental needs of developmentally disabled children, whose motor control and intellectual abilities often require the development of alternative preventive procedures to combat caries and periodontal diseases that beset them.

For the nation's children in general, the Association supports the measures advanced by the American Academy of Pediatric Dentistry to eliminate known causes of tooth decay in infants and children, most especially:

- eradication of "nursing bottle syndrome," i.e., the development of multiple carious lesions in young children as the result of using a nursing bottle, containing milk, formula, fruit juice or sweet liquid, as a bedtime pacifier.

A public education initiative is recommended to warn parents of the danger of this practice. In the health community, increased awareness of the problem should be sought among hospital professionals.

Additionally, as a member of the Healthy Mothers, Healthy Babies Coalition, the Association is cooperating in the development of cautionary language for baby bottle package labels and inserts, stating that babies should not be put to bed with bottles inasmuch as prolonged contact with milk, juice, formula or sweet liquids may cause severe tooth decay. To date, one bottle manufacturer has agreed voluntarily to provide labeling and inserts of this kind with its product.

- early instruction of parents in infant oral hygiene, emphasis on the value of systemic fluoride and detection of infant habits or muscular imbalance which can lead to malocclusion of teeth and dental caries.

Parental consultation with a dentist prior to an infant's first birthday is recommended, as is an early dental examination of the infant.

- placement of pit and fissure sealants on permanent molar teeth soon after they erupt and exposure to proper levels of systemic fluoride from birth through age 16.

The combination of these measures increasingly is recognized as the most effective method of preventing caries in children. Systemic fluoride is best provided through fluoridation of community water supplies. Where this is currently unavailable, fluoride supplementation may be achieved through drops or tablets. Additionally, twice daily use of a fluoride dentifrice for infants, young children and teenagers is strongly recommended.

These alternatives and supplemental measures, it must be noted, do not represent a comparable preventive dental health initiative to fluoridation of community water supplies. They are less effective, require ongoing parental supervision, and are more costly and, thus, less available to our entire society. The influence of the Congress should be directed toward providing water supply fluoridation to the 70 to 100 million Americans who remain without it.

The Association is prepared to assist the Committee in any appropriate way in the development of legislation to improve public health and public education programs to more fully address the dental needs of children.

Thank you for your consideration of our views.

AMERICAN MEDICAL ASSOCIATION

535 NORTH DEARBORN STREET • CHICAGO, ILLINOIS 60610 • PHONE (312) 645-5000 • TWX 910-221-0300

June 9, 1988

The Honorable Lloyd Bentsen
Chairman
Committee on Finance
205 Dirksen Building
Washington, DC 20510

RE: Statement for the Record of the May 24 Committee on Finance Hearing on Primary Health Care for Children

Dear Senator Bentsen:

The American Medical Association requests that the enclosed AMA report on adolescent health be submitted for the record of the May 24 Senate Committee on Finance hearing on the issue of Primary Health Care for Children.

The AMA has long been committed to promoting the improved health and well-being of children. Our purpose in publishing this third report is to better focus concern about the variety of health risks that adolescent children face, including substance abuse; sexuality and pregnancy; victimization; emotional disorders and suicide; developmental and other physical problems; and violence and sociopathy.

The AMA believes this document is a valuable resource of information on the health needs of adolescent children. We are certain that the widespread availability of information about adolescent health can result in health care interventions that will have life-long beneficial impact on individual lives.

Sincerely,

James H. Sammons, M.D.

3803p

enclosure

REPORT OF THE BOARD OF TRUSTEES

Report: KK
(A-88)

Subject: Adolescent Health: Background Report

Presented by: Alan R. Nelson, M.D., Chairman

Referred to: Reference Committee E
(J. Edward Hill, M.D., Chairman)

ABSTRACT

The AMA White Paper on Adolescent Health focuses on many pressing health issues facing adolescents. These problems have deep and complex roots that are related at least in part to current economic realities and the attitudes and values of our culture. Although this dependence sometimes is mentioned in discussions of adolescent health, seldom is it explored adequately to yield an understanding of the relationships between societal characteristics and adolescent health. This background paper addresses these relationships by focusing on the following issues:

Economic Realities

- Adolescents frequently work in service or retail industry jobs. On the average, it takes two retail sector jobs to equal the pay of one manufacturing job.
- The income from a minimum wage job will not support an intact family of three above the poverty level.

Family, Community and the Role of Adolescents

- Adolescents spend very little time with adults, either at school, in the workplace, or at home. Consistent and available adult role models for adolescents are not readily accessible.
- In our society there is no well-defined role for adolescents.

Family Structure

- The numbers of families headed by single women has been growing due to high divorce rates and extramarital pregnancies. Single mothers and their children are at high risk for poverty.
- In 1986, 20% of all children under the age of 18 lived in poverty.
- Two thirds of black children in female-headed households live in poverty.

Television

- Laboratory studies have shown that viewing violence on television is linked with aggressive behavior.

- On TV shows, sexual references and sexual innuendo are very common. Television ads also send clear messages about sexuality. At the same time, parents and society as a whole are preaching abstinence.

OVERVIEW

Images of troubled adolescents abound and pervade every socioeconomic stratum from teenage gangs roaming inner city ghettos to groups of affluent teenagers listlessly roaming through sprawling suburban malls. The risk of substance abuse, teenage pregnancy, and emotional disorders threaten all children as they make the transition to adulthood. Many succumb; one in four will suffer the consequences of school failure, drug abuse, teenage parenthood, crime, or delinquency.

When considering the problems that adolescents face, it is easy to focus on adolescents themselves as the root of the problem. Complaining about "kids these days" is a centuries-old tradition. Shakespeare described Elizabethan teenagers as "wronging the ancientry" while Goethe said "youth is a disease time cures." Although teenagers have always been easy marks, blaming them for their problems is a dangerous and destructive habit. It is easy to blame the teenage drug abuser, for example, for getting involved in drugs in the first place, to say the adolescent was wholly responsible for choosing this self-destructive behavior - in essence to blame the victim. This simplistic approach looks at troubled adolescents and their problems as the disease instead of as symptoms partially related to the current economic realities and the changing attitudes and values of our society and culture.

Focusing on the individual adolescent isolated from his environment obscures the role that our society and culture play in influencing and limiting the choices that are available. What is it about our society that induces almost 80% of our population to use an illicit drug by age 27? What is responsible for tripling the suicide rate among young white males in the past 30 years? Why does the United States have double the rate of teenage pregnancy compared to France even though sexual activity is remarkably similar in the two countries? We must acknowledge how our societal values about sexuality influence a teenagers' emerging sexual identity and their understanding of the risks of sexual activity. To hold adolescents wholly responsible for their lifestyle choices is to assume that they are acting independently, are unconstrained by their surrounding environment, and know and understand the consequences of their choices. This is unrealistic. The problems of adolescents cannot be approached independently of each other and of the environmental backdrop. The problems of adolescents do not lie totally within adolescents.

A teenager living in poverty who is unmotivated by school and who sees limited employment opportunities even with a high school diploma will not see a future worth investing in. Instead of "just saying no to drugs," teenagers may ask "just why not?" From a teenage girl's perspective, an early extramarital pregnancy will not foreclose any future opportunities if she perceives none. In fact, it may seem like the best alternative in an American society where success in school, work, or family are so highly valued. Schools and cultures must offer some justification for learning, and future potentials must be able to compete with everyday realities. For many, they do not. These teenagers' lifestyle choices are rooted in and shaped by the socioeconomic realities of poverty. For them, a bright and appealing future may well be the best deterrent for drug use and teenage pregnancy.

Social, cultural, and economic factors must be considered in order to devise effective intervention strategies. Focusing on the teenager's pregnancy or on the individual drug abuser diverts attention from the broader, social issues of the alarming high-school dropout rate or the lack of job opportunities for non-college youth. If runaway and "throwaway" children are simply labeled delinquent, then the important perspective of the abusive and untenable home environments, which may be the real problems, is lost. Likewise, this understanding is essential in evaluating why certain programs work in different settings. A drug intervention program originally designed for inner city youth may be ineffective for suburban teenagers.

Overemphasis on the individual troubled adolescent creates another insidious phenomenon: stereotyping all adolescents as rebellious and even dangerous. The fact is that the majority of adolescents are able to make the transition to adulthood and adult responsibility without permanent scarring. Although the consequences of an unsuccessful adolescence may seem more devastating than ever - drug abuse and its grave implications have no counterpart in the harmless adolescent experimentation so fondly remembered by many adults - some investigators estimate that the proportion of "disturbed" adolescents has remained steady over the last three decades.

The common assumption that adolescence is necessarily a period of "storm and stress" has been challenged by many researchers. Certainly adolescence is a time for trial and experimentation. It always has been. While teenagers will question their parents' authority, many still share their parents' basic values. Most disagreements revolve around routine chores and other household responsibilities, not major moral or political issues. Parents however, often feel threatened by adolescents and their peer groups and dismiss them as a separate pseudospecies in a remote world of their own. Adolescent jargon and unorthodox clothes and hairstyles reinforce this notion. Adults must try to interact with adolescents in a constructive way if the transition to adulthood is to proceed smoothly. Negative perceptions about the "generation gap" and adolescent disdain for adults impair this process.

The many well-adjusted, productive teenagers become victims of the prejudices that negative stereotypes create. Negative myths affect the quality of respect and recognition that are accorded to individual adolescents. A feeling of deep distrust and dislike between adults and adolescents is the result. If adults assume that adolescents are generally untrustworthy, there will be few opportunities for adolescents to assume adult roles and responsibilities. Even if a 25-year-old and a 17-year-old are equally qualified for a job, a stereotype of an unreliable and unstable worker will seriously handicap the 17-year-old. When adults dismiss adolescents as temporary inhabitants of a developmental or even, as some people think, a pathologic stage, it hinders a teenager's development of individuality and self-esteem, two goals that are at the very core of the adolescent experience. If adults approach adolescents with a "batten down the hatches" crisis mentality, it just may become a self-fulfilling prophecy.

Adolescence must be viewed as one of many life transitions. Some think that the transition from childhood to adulthood is no more troubled than the transition to middle or old age. This is not to deny that the problems of adolescents are serious. Certainly, lifestyle choices made in adolescence have lifelong effects that limit future choices and can compromise adult potential. But the current intense focus on the problems of adolescence without the broader perspective of this period as being meaningful and productive colors attitudes and reactions to teenagers. Frequently, adults are ready to assume the worst.

Adolescence, then, must be approached with both a very broad and very individual perspective. A broad perspective is needed to understand how our society and culture shapes the adolescent world. At the same time, adolescents should be regarded as individuals without letting negative stereotypes and myths prejudice our approach.

STATEMENT
OF THE
AMERICAN HOSPITAL ASSOCIATION
BEFORE THE
COMMITTEE ON FINANCE
OF THE
UNITED STATES SENATE
ON
CHILDREN'S HEALTH CARE ISSUES

April 20, 1988

INTRODUCTION

The health of the country's children is of great concern to the AHA's more than 5,100 institutional and 40,000 personal members. We are pleased to present our views on public programs and policies affecting children's health care, and to present AHA's recommendations to the Finance Committee on changes which would improve health care and avert financial tragedies for many families.

Each year, thousands of families face financial ruin because a child incurs health care expenses that are not covered by insurance and are beyond the family's ability to pay. In some cases, this financial catastrophe results from costly illnesses or chronic conditions. In most cases, however, the financial strain results from the complete absence of basic health care coverage, and the family's inability to afford even modest health care expenses in the absence of such coverage. Even more serious is the lack of preventive and routine care which results when financially-strapped uninsured families fail to seek care.

Of the 37 million uninsured in this country, nearly one third are children. There are several reasons why these children lack coverage. The parents and guardians of many of these children are themselves uninsured because they work for employers who do not offer group coverage. In some cases, the parents or guardians work for employers who cover the costs of coverage for employees but not dependents, or the bread-winner may purchase individual coverage but be unable to afford insurance for the entire family. More than four million uninsured children live with an insured parent or guardian.

Inadequacy of the Medicaid program, however, is the primary reason for the gap in insurance for children, particularly poor children. In 1976, Medicaid covered 65 percent of the country's poor; by 1983, it covered only 38 percent.

In 1986, the American Hospital Association identified the medical indigence problem as its highest priority, and set its policy agenda accordingly. The Special Committee on Care for the Indigent issued a report, Cost and Compassion: Recommendations for Avoiding a Crisis in Care for the Medically Indigent, which outlined a series of short- and long-term public and private strategies for addressing the problem. Since then, thousands of hours have been spent by our Chicago and our Washington offices working with Members of Congress, congressional staff, and counterparts from other organizations attempting to devise solutions.

Two major resource books have been published in connection with this effort, one focusing on public programs and one on private sector initiatives. Medicaid Options: State Opportunities and Strategies for Expanding Eligibility, was published last year to provide state hospital associations and other state actors with planning materials, analyses, methodologies and worksheets to help them assess their state Medicaid programs, and devise and cost out plans for expandsion. Our second resource guide, Promoting Health Insurance in the Workplace: State and Local Initiatives to Increase Private Coverage, analyzes who the employed uninsured are, why they are unprotected, and what approaches are being taken to increase their access to private health care coverage. This newest guide has just been published, and we will be sending copies to you shortly.

During this period, we have been heartened to see several major pieces of legislation which address the problem from the public sector and the private sector side. In particular:

- The new state options under OBRA 1986, which permit states to cover pregnant women and young children under the age of five, up to 100 percent of the federal poverty level. Twenty-six states have now exercised this option.
- Additional options under OBRA 1987, which permit states to extend coverage of pregnant women and children up to 185 percent of poverty, permit accelerated coverage of children up to age five, and new phased-in coverage up to age 8.
- A 1986 tax law reform permitting owners of unincorporated businesses to deduct as a business expense 25 percent of the cost of coverage for themselves and their families.

But much remains to be done, both in terms of public program expansions and of public policies to promote private coverage. We welcome this opportunity to identify some of these remaining gaps and to suggest some ways this committee might help to close them.

WHAT REMAINS TO BE DONE: MEDICAID

Most agree that by expanding Medicaid eligibility for the very vulnerable -- poor mothers and young children -- Congress has demonstrated its commitment to assist those most in need and has begun to repair much of the damage caused by the earlier erosion in Medicaid coverage of the poor. We must not fool ourselves, however: these new options are no panacea, even for pregnant women and children. Severe eligibility problems remain, and the program faces significant problems with payment, reimbursement, and service coverage as well.

Eligibility

The first eligibility problem stems from the fact that OBRA 1986 and 1987 offer options rather than mandates, and therefore whether or not a particular poor child or pregnant woman is covered will depend on whether or not the particular state has chosen to exercise the option, how aggressively the state chooses to be in its outreach efforts, and whether it will provide "continuous" coverage regardless of changes in family income.

Several provisions of the Medicaid Infant Mortality Amendments of 1988 (S.2122), introduced by Senators Bradley, Chafee, Mitchell, Rockefeller, Matsunaga, Durenberger, Riegle, Chiles and Daschle and currently under consideration by this committee, would be a tremendous help in addressing this eligibility problem:

- Requiring state Medicaid programs to cover all pregnant women and infants living at or below the federal poverty level. (This requirement is also stipulated in the Universal Access to Prenatal, Maternity, and Infant Care Act of 1988, S.2046, introduced by Senators Durenberger, Biden, Chiles, Weicker and Lugar).
- Requiring states to continue coverage of initially qualified pregnant women, even if a change in income puts them above the eligibility ceiling.
- Including outreach services for pregnant women and infants in the list of services for which states can claim Medicaid matching funds.
- Requiring states to implement a presumptive eligibility program for pregnant women (under which pregnant women who seem to meet the state's

income criteria could receive temporary coverage for ambulatory services, pending an official determination of eligibility).

We strongly support these and other provisions of S.2122 and S.2046 and would be pleased to assist this committee in assuring their passage.

Even as we do this, it is important that we also begin to consider some broader eligibility problems. Even if all of the states were to enact the maternal and infant care options contained in OBRA 1986 and OBRA 1987, and/or even if S.2122 and S.2046 were enacted, some very serious eligibility gaps and state-to-state inequities would remain. For one thing, women receiving coverage under any of these maternal and infant care expansion provisions would not receive full coverage, but only a "limited benefit" policy. Even if the state of Alabama were to adopt these options, for example, a single mother of two earning $1,417 a year would only be covered if she were pregnant, and then only for pregnancy-related care.

In the case of children, these options might make full coverage more available, but many very poor children can still be ineligible, even in states that adopt both the 1986 and the 1987 options. A nine-year-old living in the Alabama family described above, for example, would not be eligible, because the child would be too old for inclusion under the OBRA options and too rich for inclusion under the traditional program. If a nine-year-old lived with both parents in Alabama, the child would lack coverage even if the family income were below $1,417, because Alabama does not cover two-parent families.

Eventually, we must come to terms with the core problem: Medicaid eligibility ceilings are linked to AFDC payment levels, and these AFDC payment levels, in turn, show both tremendous interstate variation and a consistent decline over time. In 21 states, eligibility levels are now at or below 50 percent of the poverty level, meaning that dependent children and their mothers in three-person families earning more than $4,650 a year do not qualify. (Medically needy programs in some of these states raise the income ceiling somewhat, but never by more than a third.)

For these reasons we support:

- o Establishment of a minimum national eligibility floor for Medicaid, set at 50 percent of the federal poverty level.
- o A five-year plan for moving the national eligibility floor from 50 percent to 100 percent of poverty.

A final eligibility problem concerns the all-or-nothing nature of Medicaid coverage and the links between welfare and Medicaid. Typically, the entry-level jobs found by former AFDC recipients do not provide group health insurance and do not pay enough for the employee to purchase individual, much less family coverage. But they do pay enough to move the former welfare recipient beyond eligibility ceilings for Medicaid. As a result, parents often find they must choose between employment and health insurance for their families. Current federal requirements and state options provide a few months of transitional coverage, but then coverage ends.

As a solution to this problem, we support H.R. 4033, introduced by Congressman Waxman which would:

- o Require states to extend, for 24 months, Medicaid or alternate health care coverage to families who lose cash assistance under the AFDC program due to earnings and who continue to work.
- o Require states to extend, for six months, Medicaid coverage to families who lose AFDC benefits due to collection of child or spousal support.

Financing and Reimbursement

In order for states to expand eligibility, either under the OBRA 1986 and 1987 options or under a new mandated eligibility floor, more money must be brought into the system. Medicaid programs already are staggering under the burden of financing existing health care services excluded under Medicare. Care for the elderly and disabled, particularly the long-term care services excluded from Medicare, already account for three-quarters of Medicaid expenditures. In some states, programs also are absorbing a large and growing share of expenses for AIDS patients.

In the past several months, we have worked with state task forces and study groups using our Medicaid Options worksheets to develop cost estimates for the OBRA 1986 expansions. We have seen first hand how states are struggling to finance Medicaid expansion or, in some cases, struggling simply to maintain the current level of commitment. Sometimes they fail. In Illinois and Michigan, for example, hospitals and nursing homes have gone for months at a time with no Medicaid reimbursement because the state Medicaid agency ran out of funds well before the end of their fiscal year.

Financing problems have become so severe that hospitals in West Virginia and in several other states have taken up collections among themselves and donated money to the state Medicaid agency to fund the state share of Medicaid costs. More bizarre still, the Health Care Financing Administration is taking the position that this is an inappropriate way for states to raise money and that donated funds therefore should not be matched by federal dollars. (So far, HCFA's position has not been upheld in the courts.) However this drama plays out, the fact that it is occurring at all says that something is quite amiss with the existing system for financing Medicaid.

A small part of the short-term solution lies in finding responsible ways for controlling costs through case management and the use of alternative services, as discussed below. In the long term, however, the solution lies in finding an alternative form of financing for long-term care.

One way states have reacted to the financing problem is by holding down provider reimbursement, but such a strategy has serious implications for access. When reimbursement levels are too far below the levels customarily paid under private plans, newly eligible women and children often find little improvement in access to care.

Reimbursement levels are not the only factor limiting access: Physicians and hospitals alike are confounded by the complexity of the claims process, the often slow payment, the risk that claims will be rejected, or the risk that payments will be stopped when states run out of money before the end of the fiscal year. For some services such as maternity care, moreover, even private-pay patients are facing some access limitations. High malpractice premiums have led many physicians to drop or limit their obstetrical practices, thereby creating some access problems even for patients with full private coverage or independent resources.

Particularly for services such as maternity care, however, reimbursement rates clearly are going to have an effect on access. Nationally, the average payment for a maternity package for physician and hospital care was $3,440 in 1985. For Medicaid, the average payment was $2,200, and it dipped far below this in many states. In light of this, the Alan Guttmacher Institute's finding that only six out of ten obstetricians will accept Medicaid patients should come as no surprise.

The legal foundation for a solution already exists. Section 1902(a)(13)(A) of the Social Security Act requires state Medicaid programs to provide satisfactory assurances to HCFA that Medicaid payment for hospital and long-term care services provided under a state plan are reasonable and adequate to meet the costs that must be incurred by efficiently and economically operated facilities in order to provide care and services in conformity with applicable state and Federal laws, regulation, and quality and safety standards, and to assure that individuals eligible for medical assistance have reasonable access to inpatient hospital services of adequate quality. Section 1902(A)(30) of the Act requires that payments be consistent with efficiency, economy, and quality of care.

HCFA regulations have gone into considerable detail about the kinds of computations and types of proof states must submit to show that they have met the upper payment limit requirements. But there have been no details concerning what states must do to meet minimum reimbursement requirements; i.e., what kinds of evidence states must submit to prove that their rates are in fact adequate to assure access to care.

We strongly support Sec.301 of the Medicaid Infant Mortality Amendments of 1988 (S.2122) which would:

- Add to Sec.1902(A)(30) of the Social Security Act a requirement that state Medicaid payments be "sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population."
- In the case of obstetrical services, require states to submit an amendment to the state plan that specifies, by procedure, the payment rates to be used, so that the Secretary can make a determination as to their adequacy.
- Require states imposing durational limits on inpatient hospital services to establish exceptions to any such limit for medically necessary services provided to an infant up to age 1 by a disproportionate-share hospital.
- Require states which pay for inpatient hospital services on a prospective basis to specify to the Secretary the outlier adjustment that will be made in payments to disproportionate-share hospitals for eligible infants up to age 1 with exceptionally long lengths of stay or exceptionally high costs.

We believe that these provisions would go a long way toward improving access to care for pregnant women and infants. We suggest, however, that the committee consider broadening the scope of these last three requirements beyond obstetrical/infant care services and beyond disproportionate-share hospitals.

Service Coverage

Because Medicaid is a joint federal-state program, with states free to operate within general federal guidelines, states can and do vary considerably not only on the extent but on the content of coverage as well. Federal rules on covered services mandate certain services for the categorically needy and a different list for the medically needy; they leave other coverage decisions to the discretion of states. Moreover, the law permits states to limit the amount or scope of required as well as optional services.

This patchwork Medicaid system results in gaps and voids in which necessary and cost-effective services are not covered. For example, Medicaid traditionally has not paid for case management services, or for many of the support services necessary to maintain a disabled child or adult in the community. There have, however, been some recent positive developments along these lines, and we believe this progress could be accelerated through additional steps taken by this committee. For example:

- States have shown great success in utilizing a waiver option (Sec.2176) for disabled children and adults alike which allows for provision of home and community based services to Medicaid recipients who otherwise would require care in an institution. Many states, however, have been reluctant to seek a waiver because of the difficulties involved: they must prove that the estimated home care costs are lower than estimated institutional costs, and they also face limits in terms of the total number of people who can be served under a waiver.

- Given the proven cost effectiveness of community-based care for many groups currently receiving expensive institutional care under Medicaid--AIDS victims and the elderly, as well as disabled or chronically ill children--this committee might wish to consider replacing the Sec.2176 waiver provision with a straightforward state option allowing for such substitutions.

- Case management, when properly done, can improve quality of care and reduce costs. The case manager assists the client in developing an appropriate plan of care, reevaluates the plan as necessary, helps to locate and coordinate needed services, and provides follow-up. These services are particularly useful in the case of disabled or chronically ill children and adults who are likely to need frequent care from many providers.

- Congress recently gave states the option of paying for case management services in their Medicaid programs, and also permitted states to target this service to subgroups within the Medicaid population. However, it does not appear that this option is widely known. One way to encourage states to utilize it would be to provide an enhanced federal match. Therefore, this committee might wish to consider a federal match of 80 percent or even 100 percent for case management services.

Any comprehensive approach to the problem of medically indigent children must begin with Medicaid reform -- reform not only of state eligibility standards but of payment, reimbursement, and coverage as well. We have seen some important gains in the past few years, but there are many more still to be made.

WHAT REMAINS TO BE DONE: PUBLIC POLICIES AFFECTING PRIVATE COVERAGE

While Medicaid reform is a critical step in insuring the health of our nation's children, much of the problem can and should be solved in the private sector. Employer-sponsored coverage long has been the cornerstone of our pluralistic health insurance system, but there are several signs that this traditional link between work and health insurance has been eroding, particularly for children:

- Employers who offer family coverage have been cutting back on premium share, with the result that a greater part of the premium now must be paid by the worker.

- Between 1982 and 1985, the number of children covered under employer policies dropped from 36.1 million to 34.9 million.

- One fifth of all uninsured children live with a parent who has employer-sponsored coverage.

There is considerable logic, therefore, to the idea of extending coverage to many of the uninsured by building on the existing private-coverage model. The key policy question is how. Two approaches have been suggested: the use of mandates, and the use of tax supports, public subsidies, and other incentives. We believe both approaches are necessary.

Mandates

AHA supports the Minimum Health Benefits for All Workers Act (S.1265) sponsored by Senators Kennedy and Weicker and amended in February. The growing "crack" in the public and private insurance system has now become an abyss. This crisis calls for immediate strong action from the private sector as well as public programs, and this outcome is unlikely without a federal mandate. Just as employers must provide a minimum wage and a safe working environment, they have an obligation to make health insurance available to their employees.

Incentives and Subsidies

While business has an obligation to make insurance available for employees and dependents, government has the obligation to create an environment that will enable business to comply through the creation of appropriate tax incentives and other subsidies. One very sound proposal for facilitating employer-sponsored coverage is S.2234, which has been introduced by Senator Durenberger.

Among small businesses (one to nine workers), only 29 percent of unincorporated "proprietorships" (compared with 70 percent of small corporations) offer a health plan, in part because owners of unincorporated businesses are permitted to deduct only 25 percent of health insurance costs for themselves and their families as a business expense. S.2234 would remove this disincentive by permitting the 100-percent deduction already enjoyed by owners of incorporated businesses.

The many state and local initiatives and demonstration programs described in our resource guide on Promoting Health Insurance in the Workplace are showing that government can help make group health insurance more affordable in many other ways as well. Incentives range from tax credits for newly-insuring businesses, to public subsidies for coverage in low-profit businesses, and health insurance subsidies to programs that hire former welfare recipients. In the coming months, AHA's new Ad Hoc Committee on Mandated Benefits will be looking more closely at some of these options, and we will be glad to share our findings and conclusions with you at a later date.

CONCLUSION

Meeting the health care needs of children rests on our ability to insure them and adequately protect them against illness and disability. Much of the initiative must come from the private sector, since employer-sponsored coverage is the cornerstone of our pluralistic health insurance system. But business should not be required to compensate for the deterioration in public programs. For this reason, any comprehensive approach to the problem of health insurance coverage for children must begin with Medicaid reform in four areas: eligibility, finance, reimbursement, and coverage.

We appreciate this opportunity to present our views to the committee, and we look forward to working further with you to piece together an enduring solution to the problem of access to care for our nation's children.

STATEMENT
OF THE
AMERICAN HOSPITAL ASSOCIATION
TO THE
COMMITTEE ON FINANCE
OF THE
UNITED STATES SENATE
ON
CHRONIC AND CATASTROPHIC HEALTH CARE FOR CHILDREN

May 26, 1988

INTRODUCTION

The issue of chronic and catastrophic health care coverage for Americans of all ages is of great concern to the American Hospital Association's more than 5,300 institutional and 40,000 personal members. We are pleased to have this opportunity to present our views on the problem of chronic and catastrophic health care for children. Each year, thousands of families face financial ruin because a child incurs health care expenses that are not covered by insurance and are beyond the family's ability to pay. When this happens, a serious illness becomes a financial catastrophe for the entire family. Most Americans are protected against the cost of acute medical care through private insurance, Medicare, or Medicaid. But 37 million Americans face a financial catastrophe from serious illness because they lack health insurance. In addition, up to 20 million of the non-Medicare insured population also may be at risk for catastrophic acute care costs because of limitations on private insurance coverage.

All age groups are affected by the catastrophic care problem, but the reasons differ from one group to another. For the elderly and disabled, catastrophic health care expenses are the result of either inadequate Medicare coverage of catastrophic acute care costs or inadequate public and private coverage of long-term care costs. Congress is to be applauded for addressing this gap in coverage by enacting the Medicare Catastrophic Coverage Act of 1988. For children and non-elderly adults, on the other hand, catastrophic expenses are usually the result of a combination of poverty and non-existent or inadequate insurance. Therefore even relatively minor illnesses and modest medical bills can be financially crippling.

CATASTROPHIC CARE FOR CHILDREN: EXAMPLES OF THE PROBLEM

Few children require medical care that results in catastrophic expenses to their families. In any given year, fewer than 1 million children--1 percent of all children under age 21--are likely to incur out-of-pocket medical expenses greater than 10 percent of family income. When children do require extensive care, however, it can be very expensive, and costs frequently exceed available insurance. Recent case histories from hospitals around the country illustrate the range of pediatric catastrophic care needs:

* A 1-year-old girl was admitted with a diagnosis of meningitis. Her father was employed and had company insurance but not dependent coverage. The father withdrew $2,500 from an IRA to pay for her care. After two weeks of hospitalization, the bill was already $28,877.

* A 4-year-old boy was admitted after post-surgery aspiration. The child was comatose. The single mother was employed, but her company offers no group insurance. The mother applied for assistance but was denied due to her income level. The child will have long-term, complex continuing care needs. After one month of hospitalization, the family owed $70,539.97.

- A 14-year-old boy was admitted with a self-inflicted gunshot wound. His father is an uninsured self-employed carpenter. The family applied for Medicaid spend-down but may not meet eligibility requirements. The family already owes $127,661 for the first month of hospitalization.

- A newborn boy was born prematurely. His mother is single, employed, but with no group insurance. The boy may be eligible for Medicaid spend-down. The infant will require two to three months of hospitalization. After one month, the bill already is $53,223.

CATASTROPHIC CARE FOR CHILDREN: DIMENSIONS OF THE PROBLEM

Catastrophic illness is an individual human problem, which also becomes a family and community social problem. When a child has an acute or chronic disabling condition, whether as a result of birth, illness or accident, it is clearly a catastrophe. Because these conditions usually are costly, they often generate bills that tax or exceed the family's ability to pay and therefore result in catastrophic medical expenses. Even for families with private insurance, a traumatic childhood illness or a serious chronic disease or disorder can result in financial catastrophe for the family, either through increased out-of-pocket expenses or through wages lost because of time spent with an ill child.

CHRONIC OR CATASTROPHIC ILLNESS

Many catastrophic childhood illnesses or conditions can generate sizable acute care costs quickly. For example, the National Associations of Children's Hospitals and Related Institutions has testified that:

- Approximately 220,000 premature babies are born each year; with intensive care nursery charges approximately $1,000/day, average hospital charges are over $35,000 for an immature infant.

- Heart surgery for a child may cost a family $22,000 for a hospital stay.

- Treatment for extensive burns may result in a hospital bill of $45,000.

In addition, many children face chronic care needs that have a cumulative effect and are likely to be coupled with spells of acute illness.

- Comprehensive care for children with cystic fibrosis can cost a family $6,000-$12,000 annually; intermittent hospitalizations may average more than $7,000 per stay.

- Institutional care for a ventilator dependent child may amount to $350,000 annually.

Finally, care for children with mental health problems can be very costly and is often inadequately insured, leading to many undertreated problems. There is general agreement that at least 7.5 million children--12 percent of all children--need some mental health treatment; less than one-third of these children receive treatment.

CATASTROPHIC EXPENSES FOR NON-CATASTROPHIC ILLNESS

Although catastrophic acute or chronic illness is one important cause of catastrophic expense, it is not the only cause. In fact, most of the people who incur catastrophic expenses are not victims of catastrophic illness but rather are victims of poverty and lack of insurance.

The magnitude of the problem of financially catastrophic illness largely depends on the definition adopted. Some have defined catastrophic expenditures as those exceeding a specific annual cut-off figure, such as $2,000, but such definitions do not account for differences in income. For this reason, health policy researchers are more likely to use a definition that relates expenditures to income. A common definition is that catastrophic expenditures are those which exceed 10 percent of family income.

For children and non-elderly adults, the major cause of catastrophic expenses is the combination of poverty and non-existent or inadequate insurance. Almost one-fourth of the non-elderly population are either uninsured or underinsured and therefore are at risk of incurring catastrophic medical expenses; that is, they have a 5 percent expectation of incurring medical expenses exceeding 10 percent of family income. Among the poor and near-poor, more than half are at risk.

* In four of five cases, catastrophic medical expenditures result from low incomes and poor health insurance coverage, not exorbitant out-of-pocket medical expenses. Four of every five catastrophic care expenditures are for an amount under $2,000. Only 5 percent of families with catastrophic expenditures have bills exceeding $4,000.

* Of families spending 10 percent of their income on medical care, half are below the poverty level. Of families spending 20 percent of their income on medical care, two-thirds are below the poverty level.

Despite the existence of Medicaid, children comprise a large segment of the uninsured poor:

* About 40 percent of the uninsured poor are children.

* In 1984, about 5.5 million children under age 18 were uninsured and poor.

There are several reasons for this large number of uninsured children. First, the parents and guardians of many of these children are themselves uninsured because they work for employers who do not offer group coverage. Second, in some cases the parents or guardians work for employers who purchase coverage for employees but not dependents, or the bread-winner may purchase individual coverage but be unable to afford coverage for the entire family. These circumstances may account for why more than four million of the 12 million uninsured children live with an insured parent or guardian.

Inadequacy of the Medicaid program is the primary reason for the gap in insurance for children, particularly poor children. Although Medicaid is often thought to be the principal means of financing care for the indigent, it now covers less than 40 percent of the poor. Medicaid must now be viewed principally as a program of supplementary coverage for the aged and disabled medically indigent who are eligible for and receive benefits under Medicare. In 1984, barely one-fourth of Medicaid's expenditures paid for care needed by AFDC children and their families. Three-fourths of Medicaid expenditures paid for services provided to individuals already covered by Medicare: primary care and other acute care services not covered by Medicare; extended long-term care for Medicare beneficiaries; and Medicare Part B premiums. For these reasons, averting financial catastrophies will require addressing the problems of uninsured as well as underinsured children.

RECOMMENDATIONS

Any comprehensive solution to the problem of catastrophic illness among children must seek to increase the availability and adequacy of health insurance among children. This can best be achieved by expanding public programs and implementing public policies to promote private coverage. The following points detail our specific recommendations for accomplishing these ends.

MEDICAID REFORM

Congress enacted OBRA 1986 and OBRA 1987 that gave states options to expand Medicaid eligibility for the very vulnerable--poor mothers and young children. The Medicare Catastrophic Coverage Act, currently awaiting the President's signature, would require states to cover pregnant women and infants up to 100 percent of the federal poverty level. Through these pieces of legislation, Congress has demonstrated its commitment to assist those most in need and has begun to repair much of the damage caused by the earlier erosion of Medicaid coverage of the poor. Even with these changes, severe eligibility problems remain, and the program faces significant problems with payment, reimbursement, and service coverage.

Eligibility

The first eligibility problem stems from the fact that mandates under the catastrophic care bill cover pregnant women and infants only; for older children, OBRA 1986 and OBRA 1987 offer options rather than mandates. Whether a particular poor child is covered, therefore, will depend on whether the particular state has chosen to exercise the option and how aggressively the state chooses to be in its outreach efforts.

Even if all of the states were to enact the maternal and infant care options contained in OBRA 1986 and OBRA 1987, some very serious eligibility gaps and state-to-state inequities would remain. In Alabama, for example, a single mother of two earning $1,417 a year still would only be covered if she were pregnant, and then only for pregnancy-related care. Her children would only be covered if they were under age 8. Her 9-year-old would not be eligible, because the child would be too old for inclusion under the OBRA options and too rich for inclusion under the traditional program. If a 9-year-old lived with both parents in Alabama, the child would lack coverage even if the family income were below $1,417, because Alabama does not cover two-parent families.

Eventually, we must come to terms with the core problem: Medicaid eligibility ceilings are linked to Aid to Families with Dependent Children (AFDC) payment levels, and these AFDC payment levels, in turn, show both tremendous interstate variation and a consistent decline over time. In 21 states, eligibility levels are now at or below 50 percent of the poverty level, meaning that dependent children and their mothers in three-person families earning more than $4,650 a year do not qualify. (Medically needy programs in some of these states raise the income ceiling somewhat, but never by more than one-third.)

For these reasons we support:

* Establishment of a minimum national eligibility floor for Medicaid, set at 50 percent of the federal poverty level.

* A phased-in plan for moving the national eligibility floor from 50 percent to 100 percent of poverty.

A final eligibility problem concerns the all-or-nothing nature of Medicaid coverage and the links between welfare and Medicaid. Typically, the entry-level jobs found by former AFDC recipients do not provide group health insurance and do not pay enough for the employee to purchase individual, much less family coverage. But they do pay enough to move the former welfare recipient beyond eligibility ceilings for Medicaid. As a result, parents often find they must choose between employment and health insurance for their families. Current federal requirements and state options provide a few months of transitional coverage, but then coverage ends.

As a solution to this problem, we support H.R.4033, introduced by Congressman Henry Waxman which would:

* Require states to extend, for 24 months, Medicaid or alternate health care coverage to families who lose cash assistance under the AFDC program due to earnings and who continue to work; and

* Require states to extend, for six months, Medicaid coverage to families who lose AFDC benefits due to collection of child or spousal support.

Enrollment

For all Medicaid-eligibles, and particularly for new eligibility groups, there tends to be a large gap between the number of eligibles and the number of enrollees. Those caught in the middle may needlessly incur sizable catastrophic costs and may also delay necessary care. To address this problem, we recommend two federal Medicaid initiatives:

- Establishment of guidelines for making the Medicaid application process easier and less time-consuming, and for facilitating "one-stop shopping"; and
- Giving state Medicaid agencies financial incentives to increase program participation.

Potentially, hospitals can play an important role to help close this enrollment-eligibility gap through outreach activities or by outstationing Medicaid workers. AHA is strongly committed to supporting hospitals in this activity, and work already has begun on another in our series of indigent care resource guides that will provide technical assistance to hospitals and other organizations wishing to play this role. We would be very interested in working with this Committee to devise cooperative strategies for facilitating enrollment.

Financing and Reimbursement

For states to expand eligibility, more money must be brought into the system. Medicaid programs already are staggering under the burden of financing existing health care services excluded under Medicare. Care for the elderly and disabled, particularly the long-term care services, already accounts for three-fourths of Medicaid expenditures. In some states, programs also are absorbing a large and growing share of expenses for AIDS patients.

In the past several months, AHA has worked with state task forces and study groups using worksheets from our publication Medicaid Options to develop cost estimates for the OBRA 1986 expansions. We have seen first hand how states are struggling to finance Medicaid expansion or, in some cases, struggling simply to maintain the current level of commitment. Sometimes they fail. In Illinois and Michigan, for example, hospitals and nursing homes have gone for months at a time with no Medicaid reimbursement because the state Medicaid agency ran out of funds well before the end of their fiscal year.

One way states have reacted to the financing problem is by holding down provider reimbursement, but such a strategy has serious implications for patient access to needed services. When reimbursement levels are too far below the levels customarily paid under private plans, newly eligible women and children often find little improvement in access to care.

The legal foundation for a solution already exists. Section 1902(a)(13)(A) of the Social Security Act requires state Medicaid programs to provide satisfactory assurances to HCFA that Medicaid payment for hospital and long-term care services provided under a state plan are reasonable and adequate to meet the costs that must be incurred by efficiently and economically operated facilities to provide care and services in conformity with applicable state and Federal laws, regulation, and quality and safety standards. In addition, payment must be reasonable and adequate enough to assure that individuals eligible for medical assistance have reasonable access to inpatient hospital services of adequate quality. Section 1902(A)(30) of the Act requires that payments be consistent with efficiency, economy, and quality of care.

HCFA regulations have gone into some detail about the kinds of computations and types of proof states must submit to show that they have met the upper payment limit requirements. But there have been no details concerning what states must do to meet minimum reimbursement requirements; i.e., what kinds of evidence states must submit to prove that their rates are in fact adequate to assure access to care.

For expanded eligibility to translate into improved access, there must be clear criteria and procedures for scrutinizing the adequacy of reimbursement rates. For example, the Medicaid Infant Mortality Amendments of 1988 (S.2122) would have strengthened this requirement in several ways including:

- Adding to Sec.1902(A)(30) of the Social Security Act a requirement that state Medicaid payments be "sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population";
- Requiring states to submit an obstetrical services amendment to the state plan that specified, by procedure, the payment rates to be used, so that the Secretary can make a determination as to their adequacy;
- Requiring states imposing durational limits on inpatient hospital services to establish exceptions to any such limit for medically necessary services provided to an infant up to age 1 by a disproportionate-share hospital; and
- Requiring states that pay for inpatient hospital services on a prospective basis to specify to the Secretary the outlier adjustment that will be made in payments to disproportionate-share hospitals for eligible infants up to age 1 with exceptionally long lengths of stay or exceptionally high costs.

Provisions such as these, particularly if broadened to include services beyond obstetrical/infant care services and beyond disproportionate-share hospitals, could go far toward improving access to care. We would welcome the opportunity to work with this committee on development of methodologies and strategies for assuring that reimbursement levels are in fact adequate to assure access.

Service Coverage

Because Medicaid is a joint federal-state program, with states free to operate within general federal guidelines, states can and do vary considerably not only on the extent but on the content of coverage as well. Federal rules on covered services mandate certain services for the categorically needy and a different list for the medically needy; they leave other coverage decisions to the discretion of states. Moreover, the law permits states to limit the amount or scope of required as well as optional services.

This patchwork Medicaid system results in gaps and voids in which necessary and cost-effective services are not covered. In particular, this system often make it difficult for states to implement cost-effective mechanisms for addressing the catastrophic and chronic care needs of children. For example, Medicaid traditionally has not paid for case management services, or for many of the support services necessary to maintain a disabled child in the community. There have, however, been some recent positive developments along these lines, and we believe this progress could be accelerated through additional steps taken by this committee.

States have shown great success in utilizing a waiver option (Sec.2176) for disabled children and adults alike which allows for provision of home and community based services to Medicaid recipients who otherwise would require care in an institution. Many states, however, have been reluctant to seek a waiver because of the difficulties involved: they must prove that the estimated home care costs are lower than estimated institutional costs, and they also face limits in terms of the total number of people who can be served under a waiver.

Given the proven cost effectiveness of community-based care for many groups currently receiving expensive institutional care under Medicaid--AIDS victims and the elderly, as well as disabled or chronically ill children--this committee might wish to consider replacing the Sec.2176 waiver provision with a straightforward state option allowing for such substitutions.

In addition, case management, when properly done, can improve quality of care and reduce costs. The case manager assists the client in developing an appropriate plan of care, reevaluates the plan as necessary, helps to locate and coordinate needed services, and provides follow-up. These services are particularly useful in the case of disabled or chronically ill children and adults who are likely to need frequent care from many providers.

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Any comprehensive approach to the problem of medically indigent children must begin with Medicaid reform--reform not only of state eligibility standards but of payment, reimbursement, and coverage as well. We have seen some important gains in the past few years, but still much remains to be done.

PRIVATE COVERAGE

Although Medicaid reform is a critical step in insuring the health of our nation's children, much of the problem can and should be solved in the private sector. Employer-sponsored coverage long has been the cornerstone of our pluralistic health insurance system, but there are several signs that this traditional link between work and health insurance has been eroding, particularly for children:

* Employers who offer family coverage are cutting back on premium share. As a result, the employee is paying a greater part of the premium.

* Between 1982 and 1985, the number of children covered under employer policies dropped from 36.1 million to 34.9 million.

* One fifth of all uninsured children live with a parent who has employer-sponsored coverage.

There is considerable logic, therefore, to the idea of extending coverage to many of the uninsured by building on the existing private-coverage model. The key policy question is how. Two approaches have been suggested: the use of mandates, and the use of tax supports, public subsidies, and other incentives. We believe both approaches are necessary.

Mandates

AHA supports the Minimum Health Benefits for All Workers Act (S.1265) sponsored by Senators Kennedy and Weicker and amended in February. The growing "crack" in the public and private insurance system has now become an abyss. This crisis calls for immediate strong action from the private sector as well as public programs, and this outcome is unlikely without a federal mandate. Just as employers must provide a minimum wage and a safe working environment, they have an obligation to make health insurance available to their employees.

Incentives and Subsidies

While business has an obligation to make insurance available for employees and dependents, government has the obligation to create an environment that will enable business to comply through the creation of appropriate tax incentives and other subsidies. One very sound proposal for facilitating employer-sponsored coverage is S.2234, introduced by Senator Durenberger.

Among small businesses (one to nine workers), only 29 percent of unincorporated "proprietorships" (compared with 70 percent of small corporations) offer a health plan, in part because owners of unincorporated businesses are permitted to deduct only 25 percent of health insurance costs for themselves and their families as a business expense. S.2234 would remove this disincentive by permitting the 100-percent deduction already enjoyed by owners of incorporated businesses.

The many state and local initiatives and demonstration programs described in our resource guide on Promoting Health Insurance in the Workplace are showing that government can help make group health insurance more affordable in many other ways as well. Incentives range from tax credits for newly-insuring businesses, to public subsidies for coverage in low-profit businesses, and health insurance subsidies to programs that hire former welfare recipients. In the coming months, AHA's new Ad Hoc Committee on Mandated Benefits will be looking more closely at some of these options, and we will be glad to share our findings and conclusions with you at a later date.

CONCLUSION

Meeting the catastrophic health care needs of children rests on our ability to insure them and adequately protect them against illness and disability. Much of the initiative must come from the private sector, since employer-sponsored coverage is the cornerstone of our pluralistic health insurance system. But business should not be required to compensate for the deterioration in public programs. For this reason, any comprehensive approach to the problem of health insurance coverage for children must begin with Medicaid reform in four areas: eligibility, finance, reimbursement, and coverage.

We appreciate this opportunity to present our views to the Committee, and we look forward to working further with you to piece together an enduring solution to the problem of access to care for our nation's children.

TESTIMONY OF THE CYSTIC FIBROSIS FOUNDATION BEFORE THE SENATE COMMITTEE ON FINANCE

May 26, 1988

Mr. Chairman and Members of the Committee:

On behalf of the Cystic Fibrosis Foundation, I want to thank you for the opportunity to submit testimony on our concerns for children's health issues. I offer my observations as the president and chief executive officer of the Foundation, but more importantly, as the parent of a twenty-one-year-old son with cystic fibrosis.

While much recent attention has been focused on the lack of access and affordability of health care for the growing elderly population, I would like to discuss a population that faces the tragedy of insurmountable health bills at a far earlier age. I believe that examining the plight of children and young adults with cystic fibrosis -- the most common, fatal genetic disease in America -- can provide this Committee with a gauge by which to measure current limitations and future possibilities for health care financing for all ages.

Those who suffer from cystic fibrosis (CF) and their families are not unlike the elderly in facing extreme financial difficulties brought on by illness. The difference is that cystic fibrosis strikes young families before they even have the chance to build up assets, imposing a warrant of financial hardship and inadequate access to health care with the birth of a child.

This genetic disease occurs once in every two thousand live births. The disease causes the body to produce a thick mucus which clogs the lungs and impairs digestion, ultimately leading to death from repeated lung infections and lung damage. Improved treatments, including advanced antibiotics, pancreatic enzymes, and physical therapy, now enable half of the children with CF to live into their early twenties and beyond. Moreover, research on this disease holds the promise of new treatments in the future.

However, the cost of care -- especially when a family is excluded from the private, for-profit insurance system in this country, as many of them are -- can drain a family both emotionally and financially. The CF treatment regimen consists of up to 60 pills a day to aid digestion and prevent or control deadly lung infections, combined with daily physical therapy where children are clapped on the back and chest in various positions to try to dislodge the sticky mucus. With one or more two-week visits to the hospital for intensive antibiotic therapy, the average patient can face some $20,000 per year in medical costs. Hospital visits, physical therapy, medications, and use of oxygen increase as the disease progresses, bringing families $100,000 yearly medical bills that haunt their lives now and shape future lives of poverty. The magnitude of this health care burden is evident in the estimated $300 million bill that these families are somehow supposed to pay each year.

We could provide many individual examples of the tragedy unaffordable and unattainable health care has caused families with CF. Stories where parents have been locked into jobs because if they were to move they would lose health insurance coverage for their child. Cases where parents have been forced to stay home to care for their child, only to find that obtaining an individual insurance policy for an individual with CF is next to impossible. Their experiences include the painful discoveries of exorbitant insurance premiums reaching $1000 per month or more; pre-existing condition clauses excluding the very health care that is most needed; and long enrollment periods with no provisions for interim health care costs. These are the horrors that families face daily as they strive to find a way to afford the care their children need. If they look to the government for help, they find that the idiosyncracies of a particular state's eligibility requirements and coverage determines their fate. If they look to federal programs, Supplemental Security Income or Disability Insurance, they find that their child must already be disabled and their family poor to qualify.

In essence, families affected by CF face a double-edged version of the proverbial "spend-down" associated with chronic, catastrophic illness. Not only must they sink to the level of poverty to receive government assistance, but they must watch helplessly while the disease progresses to the point where the child's health is "spent-down" so as to be legally disabled and eligible for assistance. The spend-down in finances dooms many families to a life of poverty that they cannot ever arise from; in a progressive disease like CF, the spend-down in health is even more final.

There is one group of individuals with CF that especially symbolizes the tragedy of catastrophic illness today. These are the young adults with CF -- those who have managed to survive into their late teens, twenties and thirties. For them, the victory of winning against this disease long enough to see adulthood is brought face-to-face with an insurance system designed to make them losers. Many of the CF adults who were covered by their parents' insurance policies find that at age 18, or 20, or 21, they are kicked out of the health insurance nest. In the few cases where they can be kept under their parents' policy, the price is high -- a forced "dependent" status for an individual who has more than earned the right to live as a young adult. To remain a dependent on their parents' plan, many CF adults forsake marriage or career plans, kept prisoners by the only insurance they can get.

For those who can or must work full-time, CF adults face rejection from companies that refuse to hire them for fear that they will negatively affect the group insurance plan. In some states, adults with CF face another rejection in aid programs. Even if they were covered as children under Crippled Childrens Services, they discover there are no provisions for them in adulthood. The pervasiveness of these problems was evident in the Cystic Fibrosis Foundation's most recent survey of CF families on insurance. The survey found that one hundred percent of the adults who responded had difficulty getting insurance, with thirty percent of these adults having absolutely no insurance. More than half of those insured described their coverage as inadequate.

Their problems repeat a theme of four basic insurance needs that can be achieved with your leadership. Therefore, the Cystic Fibrosis Foundation respectfully suggests the following as critical touchstones in any insurance legislation:

1) ACCESS FOR THOSE WITH PRE-EXISTING CONDITIONS.
As a genetic condition, cystic fibrosis is present from birth. Therefore, our children and young adults do not have the luxury of joining a good insurance plan and then developing CF, a situation in which they might receive adequate coverage. Instead, the "pre-existing condition" label is attached to them even when they are in fairly good health, often leading to rejection from ever joining a traditional insurance plan.

2) REASONABLE PREMIUMS.
All the insurance plans in the world will not provide health coverage if the premiums are unaffordable. Those whose finances are already stretched with daily CF care generally find it impossible to pay the prohibitively expensive premiums associated with an individual insurance policy. Moreover, many insurance companies require that the premium be paid for an entire year

before any costs associated with cystic fibrosis or any pre-existing condition are covered. Therefore, even families who might be able to afford the premiums are forced instead to use their money to pay for the health care needed now.

3) RECOGNITION OF ALL HEALTH CARE COSTS.

It is well known that insurance companies do not pay every cost associated with every health care condition. For CF, such costs go beyond deductibles and over-the-counter medications to include home health care, special diets, durable medical equipment, oxygen and medical services such as respiratory therapy. Any of these costs associated with the regular care of CF can be enough to deplete a family's assets. The alternative, not to provide care or supplies, is often a precursor to death. Many adults with CF cannot afford the antibiotics or pancreatic enzymes that would maintain their health. Legislation to improve access to health care must do more than address the hospital setting; it must address the many facets of good health care that can keep people out of the hospital.

4) WIDER ELIGIBILITY FOR HEALTH PROGRAMS -- NOT DEMANDING POVERTY OR TOTAL DISABILITY.

Just as the high everyday costs of CF are ignored thus encouraging acute care conditions, the current system of financial assistance for those who have already expended all their assets addresses the problem of financing too late. Its victims are the middle and lower-middle classes, who do not have the resources to pay for a long-term illness entirely by themselves, but are not poor enough to immediately qualify for assistance. The creation of a plan that does not base eligibility on poverty or total disability could enable families affected by cystic fibrosis and other chronic, catastrophic illnesses to secure health care at a survivable cost.

These basic insurance concerns are vital components of any comprehensive insurance program to adequately address the health insurance needs of Americans. In addition, the Cystic Fibrosis Foundation would like to make several more recommendations to improve the effectiveness of present programs:

1) INCREASED FUNDING FOR BIOMEDICAL RESEARCH

Increasing support of biomedical research into the inborn errors of metabolism is imperative to enable further understanding of cystic fibrosis and other genetic diseases. The Foundation requests that scientific opportunities offered by CF research centers continue to be recognized by the appropriation of additional, special support through the National Institutes of Health. Vital dollars contributed to the National Institutes of Health and the Cystic Fibrosis Foundation's research efforts are helping to find a cure for CF and will ultimately reduce federal spending on health care.

2) INCREASED FUNDING FOR MATERNAL AND CHILD HEALTH BLOCK GRANT

In an effort to reinforce federal commitment to health care of mothers and children, the Foundation recommends increasing funding of the Maternal and Child Health (MCH) Block Grant. These additional funds would enhance health care services provided to needy families who are ineligible for other federal programs, such as Supplemental Security Income and Medicaid, but cannot afford or obtain adequate health insurance. In order to meet the continued, but often unmet, health needs of adults with CF, we also encourage the development of state-oriented legislation to increase availability of and funding for services to adults with chronic illnesses through the Crippled Children's Services.

3) ENHANCED RESPONSIVENESS OF PROSPECTIVE PAYMENT SYSTEM TO NEEDS OF ADULT PATIENTS WITH CF

The prospective payment system must adequately address the needs of all patients with CF to avoid potential reimbursement problems. Through the assistance of the National Association of Children's Hospitals and Related Institutions, Inc. (NACHRI), children with CF have obtained a specific reimbursement category, or diagnosis-related group (DRG), to allow hospitals to obtain proper reimbursement for treating children with CF. However, young adult patients have not received this assistance and hospitals that routinely care for people with CF may be discouraged from accepting these patients due to high, unreimbursed costs. Recognizing and meeting the necessary costs to treat patients with CF of all ages would ensure access to vital health care treatments.

Options for meeting the health care needs listed above have recently gained greater public awareness. Whatever solution is ultimately chosen, we cannot overemphasize the need to include the young adults with continuing health needs as an integral part of that picture.

One option under consideration is a catastrophic illness risk pool system for the medically uninsurable. The Cystic Fibrosis Foundation enthusiastically supported risk pool legislation during the 99th Congress, despite the disappointing results that merely encouraged and did not require states to set up risk pools.

We would encourage any efforts to consider risk pools as a means for making health care accessible to individuals with catastrophic illnesses. For such state-oriented legislation to be effective, however, it must mandate and provide support for state participation. We would also request that the Committee pay close attention to the cost of risk pool premiums, in order that the risk pools provide an actual alternative to individual insurance coverage costs. Ultimately, a sliding scale or subsidized premium may be essential for those who otherwise cannot afford to buy risk pool or alternative types of coverage.

Regarding other potential solutions, we ask the Committee to consider closing the gaps in the public and private health financing programs already in existence. A federal program solution could be a Medicaid buy-in system, enabling those above the poverty level who cannot obtain insurance elsewhere to buy into the Medicaid system on a sliding scale. We also urge you to make private insurance companies a part of the solution by ensuring that they offer reasonably priced coverage that does not automatically exclude the services and people who need it most.

We also ask that the considerations raised above be implemented, for they will truly determine whether the current hardships of those facing chronic, debilitating illness receive relief. Those who suffer from cystic fibrosis and other catastrophic health problems can individually show great strength and commitment in the face of illness, as seen in our children who survive into adulthood. But those same "fighters" cannot win against a health care system that overlooks their very health needs.

Mr. Chairman, the Cystic Fibrosis Foundation thanks you for your recognition of the need for improved access to health care for all Americans, especially the needs of children and young adults, and we support your efforts to find a solution that will make health care accessible to every American.

United States General Accounting Office

Testimony

Obtaining Care for Chronically Ill Children in the Home Based Setting

Statement of
J. William Gadsby, Associate Director
Human Resources Division

Before the
Committee on Finance
United States Senate

Mr. Chairman and Members of the Committee:

I am pleased to have the opportunity to summarize our review of the barriers to home and community based care for seriously chronically ill children. It is estimated that about 1 million children fall into this category. You asked us to review the experiences faced by families in obtaining medical and other support care for them, with the objective of identifying barriers to obtaining care. Our study focused on 10 medical conditions covered in a 1985 study of childhood diseases at Vanderbilt University. These were

Juvenile-Onset Diabetes
End-stage Renal Disease
Spina Bifida
Congenital Heart Disease
Cystic Fibrosis
Leukemia
Asthma
Cleft Lip and Palate
Sickle Cell Anemia
Muscular Dystrophy

According to the Vanderbilt study, an examination focusing on families with children having these conditions would provide a good indicator of the costs and problems parents face in obtaining home care for a wide variety of chronic illnesses.

We have completed about half of our planned work. We visited children's hospitals and public and private providers in five localities (Dallas, Atlanta, Los Angeles, and Cincinnati, and the District of Columbia and adjacent Prince George's County in Maryland). We also received questionnaire responses from 197 families with seriously chronically ill children in these localities and held focus group interviews with 40 parents. Our observations today are based on this work. We plan to visit nine more localities during the next 2 months.

Families Require Wide Range of Medical and Support Services

Our questionnaire survey shows that parents of seriously chronically ill children require a wide range of medical and support services. All but two families who returned the survey said they used 1 or more of 14 services identified as being important to children and families in the home or community setting. Parents indicated that medical services were required more often than support services. The medical services required most frequently were doctor office visits and medications. The support services required most frequently were baby sitting, counseling, day care, and transportation.

Obtaining Needed Services Can Be Difficult

Although over half of the families reported they were able to obtain all services they felt they needed, the remainder reported difficulty obtaining one or more of the services. The most frequently needed medical services were not difficult to obtain. However, doctor home visits, seen as needed by only a few parents, were difficult to obtain by over half of them.

Support services seemed to present greater difficulties. Many parents experienced problems obtaining two or more of them. Unlike medical services, the frequently needed support services, day care and baby sitting, were difficult to obtain.

Perhaps most informative were our focus group discussions with 40 parents and interviews with parent support groups. These tended to center on problems in obtaining support services for the family rather than on medical care for the child. Parents told us they had difficulty finding providers of day care, respite care, and baby sitting who would serve chronically ill children. When parents found providers, the services were sometimes too expensive for families to obtain. The importance of these types of services, as well as the need for family counseling to deal with the trauma of having and caring for a seriously chronically ill child, was a common theme expressed by these parents.

Inadequate Information and Financing

Our work indicates that the access problems for both medical and support services are primarily related to inadequate information at the time of discharge from a hospital and a lack of financing. As you know, children's hospitals have discharge planning processes and provide written home care plans to help the parent and the child with the transition from the hospital to the home. Our work in several hospitals shows these processes and plans tend to focus on the medical care needed by the child and usually do not address the support services needed by the family.

Parents told us that hospital discharge planning was good in preparing them to meet the health care needs of children at home. They were often told about the medical needs of the child and were provided with training and written instructions addressing medication types and frequencies, the need for and frequency of therapies, and needed equipment and supplies. But some parents told us that they did not receive enough information on medical service providers or how the services could be financed. Many more parents said that they were not provided information on the availability of support services. They said that because there was no central source of information on providers and services, they had to go through an extensive search process before they either found providers or learned that the services were not available. Among the sources parents used to obtain information about services and providers were telephone directories, other parents, and support groups.

Parents also told us they needed help particularly during the child's first weeks at home. Parents said the transition to the home environment would have been easier if someone had made follow-up visits during the first week after discharge and helped them obtain needed medical and support services. A case manager, who could make the transition from hospital to home easier, was seldom provided.

In the financing area, the lack of public financing and/or private insurance for some medical and support services needed in the home environment was of primary concern to parents. On the medical side, parents said they experienced problems obtaining reimbursement for certain medications and therapies. Also, insurance copayments mounted up quickly and became a financial burden for some families. However, the child's medical needs were generally met.

Paying for support services and special items needed to keep the child at home was more of a problem because these items are often not covered by public financing and private insurance. Examples frequently cited were day care, baby sitting, and certain special medical items, such as the nutritional needs and vitamin supplements for diabetic children.

Easing the Access Problems

Our work suggests that greater use of case management could ease the access problems caused by inadequate information about service availability. The Department of Health and Human Services' task force report on technology-dependent children contains a definition of case management that applies to the broader population of seriously chronically ill children. It provides for a single service coordinator--the case manager--and, among other things, addresses the need for medical and support service information, planning, and coordination. Providing a case manager would be a positive step in helping parents obtain needed services, especially in the child's first weeks at home. The case manager could furnish information on both medical and support services in the community and possible funding sources, and participate in the development of the written home care plan.

Many children with the 10 medical conditions we studied are treated in children's hospitals. These hospitals seem to be the logical place to lay out a complete plan for the child's transition home and identify someone to help carry out the plan.

STATEMENT OF THE
STATE MEDICAID DIRECTORS' ASSOCIATION
OF THE
AMERICAN PUBLIC WELFARE ASSOCIATION

FOR THE
SENATE FINANCE COMMITTEE
HEARING ON CHILDRENS' HEALTH CARE ISSUES
CHRONIC ILLNESS

Mr. Chairman, the State Medicaid Directors' Association of the American Public Welfare Association welcomes this opportunity to present to the Senate Finance Committee our views on children's health care, specifically care for chronically ill children. The Chairman of the State Medicaid Directors' Association (SMDA), Mr. Aaron Johnson, recently served on the Congressional Task Force on Technology Dependent Children. While there are many aspects to the problem of provision of services for chronically ill children. SMDA will focus its remarks primarily on the care of technology dependent children.

CHRONIC CARE FOR TECHNOLOGY DEPENDENT CHILDREN:

Advances in medical technology, which enable seriously ill children to survive and live longer lives, have far outstripped the pace of our nation's development of a comprehensive humane and equitable health care policy to address the needs of these children. We believe that access to services and financing care for technology dependent children is an important and growing issue that the nation must better address.

Technology dependent children suffer a chronic disability which requires the routine use of a specific medical device to compensate for the loss of a life-sustaining bodily function. These children require on-going daily care and monitoring by trained personnel. The number of these children needing specialized services are growing: survival rates of low birthweight, premature, and seriously ill infants have increased; children who develop chronic illnesses and disabilities live longer lives due to technological advances; and AIDS infection rates among newborns continues to rise.

The need for on-going high technology care will increase as technology continues to advance and as children continue to be born with, or develop early in life, life-threatening diseases and disabilities. We believe that a way must be found to provide appropriate care for technology dependent children that maintains life support and provides an environment that encourages growth and development of the child. Appropriate care also necessitates the development of an individualized plan of care that is family centered, comprehensive, coordinated, cost-effective and community-based where possible.

SHORTFALLS OF THE CURRENT SYSTEM:

SMDA believes that current policies and regulations which guide the care of technology dependent children are not necessarily conducive to the development of the appropriate care. The lack of policies that promote development of community based settings, services and personnel; an uncoordinated patchwork of public programs; the inadequacy or unavailability of private health insurance; and the limited, national-level efforts to coordinate and develop educational and outreach programs are some of the problems experienced by technology dependent children and their families. As Medicaid Directors we are particularly concerned about access to care and therefore will address those issues that affect access to appropriate care for this group of children.

While our testimony does not focus specifically on financing issues, this area is a major concern of state Medicaid directors and we wish to raise one point - - as in the case of long term care services for the elderly and disabled, the Medicaid program by default, has become the primary payor of care for technology dependent children. Many criticisms have been leveled against Medicaid in terms of its inequitable eligibility criteria across states, inadequate alternative service delivery settings, and low provider reimbursement rates. While we do not disagree with many of these issues, we do point out that Medicaid is bearing a even greater share of the financial burden of financing care for chronically ill children. This is why we strongly believe that a more coordinated national-level policy must be developed which includes an emphasis on increased efficiency of public programs through coordination of services and development of appropriate settings, and more responsibility placed on private insurers to cover the care of these children.

SMDA believes that much can be done to provide more appropriate care and the remainder of this testimony focuses specifically on four main problem areas including: lack of access to both alternative and traditional services; inadequate coordination among the various agencies that provide and/or finance services; unavailability of comprehensive information about services and funding sources; and lack of targeted outreach to ensure appropriate preventive maternal, prenatal and infant care.

Access To Care:

Many barriers that preclude access to care for technology dependent children exist in the areas of financing and delivery settings.

In the private sector, many insurance policies will not cover the extended care needs of technology dependent children. If services are covered, the premium and deductible costs can cause severe financial hardship on the families of these children. In many cases, limited coverage leads to disruptions in care when families have exhausted policy benefits. Additionally, private insurers will often cover only those services provided in an institutional setting, which eliminates the possibility for more appropriate community or home-based care.

In the public sector, Medicaid is the primary payor for services of technology dependent children. The predominant care setting covered by Medicaid is the acute cae hospital. In many cases this is not the most appropriate form of care. Medicaid programs are restricted by current program waiver requirements that make provision of home and community-based services difficult because the waiver process is cumbersome, time-consuming, and uncertain.

In both the private and public sectors, there is virtually no coverage for respite care services. These services are vital if families are to be able to care for their children at home by providing much needed support and relief. The strain on families that continuous home care can create is such that, without relief, families are often forced to place their children in institutional settings.

Even if a family can secure financing for care, there is a notable lack of providers throughout the country. Of particular concern, is the lack of any adequate continuum of care services needed to meet the diverse and changing needs of this population. There has been no encouragement for the development of a full spectrum of service settings including: acute care, transitional facilities, rehabilitation facilities, small group homes, respite and medical day care services.

Inter-Agency Coordination:

A significant feature of the current systems which finance and provide care for technology dependent children is the lack of coordination. In the public sector particularily, there are often complex and conflicting regulations and eligibility requirements, inordinate amounts of paperwork, program inflexibility, service delays and inter-agency disagreements that pose substantial barriers to any care, much less appropriate care.

Federal, state and local agencies are often in the position of at best, duplicating efforts, and at worst, working at cross purposes. While the various agencies may work hard to provide services and/or benefits, it has been historically difficult to come together and delineate areas of cooperation and coordination given the various jurisdictional responsibilities and duties of these agencies. There is no one agency that has been able to establish a leadership role in order to coordinate services. At the federal and state levels alone, there are over 40 separate programs that have some level of jurisdiction over technology dependent children. Inter-agency linkages are missing and there is little programmatic coordination among the states and among the different federal agencies with jurisdiction over the various programs.

While this is not an issue unique to care of technology dependent children, reform is needed in order to better utilize resources and serve the needs of this population.

Coordination of Information:

Related to the issue of inter-agency coordination is the issue of information availability and dissemination. The current system is such a patchwork of services and financing sources that most families have no clear idea of what is actually available to them.

The volume and variety of services that exist to meet the needs of the technology dependent population is such that case management services are needed to help families find their way through the maze of possibilities. Case management services are seldom a covered benefit in private policies. In public programs, case-management is not sytematically provided to families with technology dependent children. Case management with stong family participation is a necessary component for appropriate utilization of resources.

Beyond the needs of an individual family, information is poorly coordinated across the country. For example, there is no precise knowledge on the number of technology dependent children. Additionally, there is no nationally coordinated information about the types of research occurring on chronic illness, how families are dealing with the care of their children or how providers are addressing the particular and varied care needs of this population.

The need for all of these types of information will only grow more acute as the chronically ill child population increases and as people struggle for ways to address the needs of technology dependent children. Accessible information is needed so that we do not continue to reinvent the wheel each time state or local officials look for ways to address the problem of care for the technology dependent.

Outreach for Better Preventive Care:

The last topic that SMDA will address is preventive maternal, prenatal, and infant care. States have been addressing this issue for several years now. A majority of states undertook coverage of low-income infants and pregnant women up to 100 percent of poverty the federal level when it first became an option under OBRA '86.

We have made great strides in increasing survival rates of low birthweight and premature infants. It does appear, however, that we have reached a temporary hiatus in the number of lives we are able to save and the number of low birthwieght infants born in this country each year. While we have made improvements, technological advances that save lives of ill children have taken us only so far. Technology is not a substitute for adequate early prenatal care or early screening and preventive care. Health problems must be detected and prevented as early as possible in the life of a child.

Now that states are required to provide coverage for pregnant women and infants up to 100 percent of poverty as a result of the Catastrophic Care legislation, we need to turn our attention to better outreach so that families learn about services available to them. While state Medicaid agencies are available to provide critical access to health care for infants and pregnant women, without effective outreach, improved access alone will not greatly reduce infant mortality and the incidence of chronic illness among children. Outreach is needed that will stress the importance of early prenatal and child care in preventing chronic and disabling diseases among our children.

RECOMMENDATIONS/CONCLUSIONS:

In order to facilitate the provision of appropriate care for children with chronic illnesses, the State Medicaid Directors' Association would like to make the following recommendations:

- The federal government should promote the use of both public and private resources to develop of a full spectrum of services for technology dependent children -- from acute care hospitals to in-home medical and respite care including a full range of community care options.

- Medicaid agencies should be permitted to offer home and community based care alternatives as state option. The waiver process should be eliminated or greatly facilitated.
- Government should offer incentives to the private sector to promote improved, affordable, private sector coverage of chronic illness. Comprehensive coverage through the workplace should be encouraged.
- The federal government should promote greater inter-agency cooperation and coordination of services, eligibility requirements and financing at federal, state and local levels.
- Case-management services for all programs and policies covering technology dependent children should be encouraged at all levels of government and within the private sector.
- A nationally coordinated outreach campaign designed to impress the need for early prenatal and child care should be developed by the federal government.

The State Medicaid Directors' Association appreciates the leadership of the Senate Finance Health Subcommittee in the area of children's health care issues. Thank you for the opportunity to present these views on the needs of the chronically ill, technology dependent children.

STATE OF MINNESOTA
DEPARTMENT OF HUMAN SERVICES
Human Services Building
444 Lafayette Road
St. Paul, Minnesota 55155-38

June 24, 1988

Laura Wilcox, Hearing Administrator
United States Senate
Committee on Finance
Room SD-205 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Ms. Wilcox:

Re: Testimony on Children with Chronic Illnesses

Enclosed is written testimony I wish to submit regarding the support given to families with children who have chronic illnesses. I appreciate the opportunity to have input into the development of policy in this area.

Sincerely,

SANDRA S. GARDEBRING
Commissioner
Department of Human Services

AN EQUAL OPPORTUNITY EMPLOYER

Testimony on Chronic Illness

The State of Minnesota is pleased to provide testimony relating to children with chronic illnesses. The range and severity of chronic illness in children is as varied as the thousands of families who raise children with chronic illnesses. In Minnesota, we believe that families should be the primary caretakers of children with special health care needs. We attempt to practice that policy by providing services necessary to support families in their role as primary caretakers.

Minnesota is fortunate to have a state legislature as well as a congressional delegation that believes in community based, family centered care. With this legislative support, we have three home and community based Medicaid waivers, the TEFRA Option for certain disabled children, a Medicaid Program which utilizes a broad scope of optional services, as well as many state funded programs which also support families of children with special health care needs. We are able to serve a variety of families and children. However, this patchwork system of services does have some drawbacks. Among the more important drawbacks are the lack of consistent funding for services, the lack of support for families whose children do not need an institutional level of care, and the inadequacies of our private insurance plans.

One of the major frustrations encountered by families in caring for their chronically ill children is the lack of consistent funding of services. No matter what source of funding is used, parents are never sure from month to month if their child will continue to qualify. They live in fear that the program will be discontinued or their insurer will decide to no longer pay for care.

Home and Community Based Waivers are a wonderful option for states to provide creative community based services to certain children with chronic illnesses. However, the application and renewal process is so complicated and cumbersome that many states will not attempt the agonizing process. The waivers are also an unstable funding source because of HCFA's authority to limit, deny or terminate waivers with great discretion and subjectivity on their part. Waivers also require an inordinate amount of administrative time since they must be run separate from the regular Medicaid Program. Minnesota chooses to participate in waivers simply because we see families in severe need and waivers allow us to support these families.

The Medicaid Program, through home and community based waivers and the TEFRA 134 Option for certain disabled children, allows states to provide support to families of severely disabled children. However, waivers can only be used for children who would otherwise be in an institution. This is often a difficult eligibility requirement to verify. Parents are reluctant, even adamant, to say that they would even consider placing their child in an institution. We have been told by HCFA that if a parent will not say that they will institutionalize their child if they do not receive in home services, the child is not eligible for waivered services.

The TEFRA Option does not require that a child would otherwise be institutionalized, but it does require the child to need the kind of care which would normally be provided in an institution. There are many children with chronic illness that may not need the level of care provided in an institution. This is particularly true if the child has an illness that can be controlled and if controlled does not adversely affect the child's health. However, to control the illness, the family may have to spend many hours each day providing treatments and therapies. They may also have enormous out-of-pocket expenses for drugs, supplies, and routine medical care.

In addition, Medicaid has added case management as a State Plan optional services. Case management is a critical service component for families of children with chronic illnesses. However, the restrictions and limits on using case management as a State Plan optional service do not allow states to utilize case management in a manner which benefits both the family and the administration of the Medicaid Program. Case management as a State Plan option is seen as an enhanced information and referral service for which any entity can be reimbursed. What is needed is a qualified case manager who can do assessment, organize a multi-disciplinary team to work with the family, provide the family with appropriate options and choices, coordinate services to prevent duplication or fragmentation, monitor costs as well as quality of services and provide support to the family.

We've discussed children who are eligible for Medicaid, but what about children who for whatever reason are not eligible. The number of uninsured and underinsured children is growing at an alarming rate. Uninsured and underinsured are children often the children who have a chronic illness that grows worse because of lack of ongoing and supportive health care services. Even families who believe they have adequate health insurance coverage, find that few, if any, of the services that the family may need to care for their child at home, are reimbursed by their insurance company. Because of inadequate support of community care services families experience increased stress and are often driven to drastic measures. Sometimes parents or siblings become physically or mentally ill because of the added responsibilities of caring for a child with special health needs. Some parents find themselves locked into jobs because they are afraid of losing health insurance, while others may not be able to move to another community or pursue educational goals. Families may become desperate, isolated and dysfunctional.

If as a society we believe that families are and should be the primary care givers of children with chronic health needs, then we as a society must demand that families are provided with adequate services which are consistently available and with financial support in caring for their children within their family home. It is time to make home and community based waivers a part of the State Plan optional services rather than an arbitrary approval/denial after a complex application process. By making waivers a state plan option, states would have more administrative time which could be better utilized in serving families. It is time to demand that insurance companies and HMOs provide adequate coverage of home health and support services for families of children with special health needs. It is time to reduce duplication and eliminate fragmentation - thereby transforming our patchwork system into an easily accessible system that will assure families have the ability to provide for the emotional, physical, social and developmental needs of their children with special health needs by providing families with the the support and funding needed to meet their children's needs.

STATEMENT
of the
NATIONAL ASSOCIATION OF REHABILITATION FACILITIES
to the
THE SENATE COMMITTEE ON FINANCE
UNITED STATES SENATE
on the
CARE OF CHRONICALLY ILL CHILDREN AND CATASTROPHIC EXPENSES

MEMBERS OF THE COMMITTEE:

This statement is submitted on behalf of the National Association of Rehabilitation Facilities (NARF). NARF is the principle national membership organization of facilities rendering medical and vocational rehabilitation services. The membership includes almost all freestanding rehabilitation hospitals in the country, a large number of rehabilitation units in acute care hospitals, outpatient rehabilitation facilities, and vocationally-oriented agencies. Medical rehabilitation facilities deal with the mitigation and remediation of disabilities caused by disease and trauma, and help people become independent. Vocational/developmental disabilities programs assist people with such disabilities to go back to work. Most, if not all, of NARF's medical membership participate in the Medicare and the Medicaid programs.

I. BACKGROUND

Rehabilitation facilities and professionals serve over 600,000 people per year suffering from major illnesses or the results of accidents. The disabled include, for example, over 10,000 people per year , many of them children and young adults, with spinal cord injuries. There are between 70,000 and 90,000 people who survive head injuries per year, of which at least ten percent are considered severely traumatically brain injured -- many of these, too, are children. Another 500,000 - 600,000 people in the United States suffer a stroke annually; approximately two-thirds suffer some degree of permanent disability.

Rehabilitation specialists render treatment to these individuals and, as well, treat individuals, including children, who suffer from burns; congenital deformities; cancer; arthritis; and neurological, musculoskeletal, pulmonary and cardiovascular diseases. The primary function of rehabilitation facilities and rehabilitation professionals is to provide diagnosis and treatment of patients for specified medical conditions both surgical and non-surgical. The average length of stay in a rehabilitation hospital is long because the objective is restoration of impaired functions which generally follow serious disease or injury. The ultimate purpose and goal of rehabilitation is to restore patients to their optimum level of function and thereby to reduce dependency. This includes restoration of strength, mobility, and all activities of daily living.

Provision of timely and effective rehabilitation services and programs to individuals, including children with chronic disabilities who have experienced disease or trauma, can greatly reduce subsequent dependence and need for acute and long-term care. Once a patient is released from a rehabilitation facility, he or she may require outpatient and home care services. Rehabilitation can minimize the need for long-term care although some persons with disabilities require continuing institutionalization when home and community care is inadequate.

II. ACCESS TO REHABILITATION CARE FOR CHILDREN WITH DISABILITIES

Today, there are over 600 medical rehabilitation hospitals and units, 150 comprehensive outpatient rehabilitation facilities, over 1,000 rehabilitation agencies and other outpatient providers and numerous home health agencies providing rehabilitation services throughout the country. There are approximately fourteen children's hospitals which specialize in rehabilitation. As of December 1987, the number of designated rehabilitation beds for 1987, according to Health Care Financing Administration (HCFA) data, totals 20,370.

Children who 15 years ago would have succumbed to diseases, injuries, and birth defects now are surviving as a result of medical advances and the use of sophisticated medical devices and services. Increasing numbers of these children are being seen and treated in rehabilitation facilities. With the aid of ventilators, intravenous feeding, and long-term drug therapy, children with these special needs are functioning in home settings and attending school.

Rehabilitation facilities that specialize in serving pediatric cases have learned that they can and should play a significant role in providing services to children with chronic disabilities. Children who are born with a severe disability, and who are dependent on technology, need to be introduced into a habilitation environment as soon as they become medically stabilized. Pediatric rehabilitation facilities which serve this population offer an environment that provides medical services in addition to infant stimulation, evaluation/diagnostic services, parent and child caretaking training, psychology, counseling, education and case management/referral. These services are coordinated through an interdisciplinary team which is supervised by a physician trained in rehabilitation and pediatrics.

Pediatric facilities have seen an increase over the past five to ten years of children, including technology-dependent children, who need a rehabilitation and habilitation program following acute care and prior to being discharged to the home. When such children are discharged from the acute care hospital directly to the home, re-hospitalization may result. Families and in-home providers may not generally be able to provide the habilitation environment which is critical in light of the complex medical, psychosocial and neurological developmental needs of the child. A number of rehabilitation facilities across the country, including pediatric rehabilitation hospitals, are not yet fully equipped to provide the level of technology these children require, primarily due to lack of trained staff and inadequate equipment.

As medical science continues to improve its lifesaving techniques, there will be more children who survive trauma but are left with severe disabilities. Few families have coverage or adequate coverage for the services they require, and the effect on them and providers of care who serve them is "catastrophic". Any legislation developed to cover catastrophic expenses for children with chronic disabilities should focus on several points: first, the needs of young people disabled by disease and trauma; second, the need for early rehabilitation services and community-based support services to reduce the number of people consigned to institutional care; and access to acute care in terms of the number of facilities available and in terms of the coverage and payment for rehabilitation services.

Consider one group that illustrates this issue -- survivors of traumatic brain injuries. There are perhaps 900,000 incidents of brain injury in the country each year. About 10% of these are traumatic. Most such injuries occur among young people who engage in risk-prone activities. Over 50% are the result of motor vehicle accidents. Many are not insured or are underinsured. Some young patients are uninsured because they are too old to be covered by a parent's health care insurance and have not obtained insurance on their own. They are uninsured because few health insurance policies cover the scope and duration of services required by these patients. These cases involve coma management, intensive care and extensive rehabilitation services, both inpatient and outpatient.

The costs of care for this population are staggering. The National Head Injury Foundation estimates that on the average a young patient with a serious traumatic brain injury will spend 60 to 90 days in intensive/acute care at costs between $120,000 and

$180,000. Such a patient will then require 90 to 120 days in a very intense rehabilitation program at an additional cost of $60,000 to $70,000 and perhaps 15 months in an extended rehabilitation program at additional costs of approximately $200,000. In serious cases, residual functional deficits require life-long support services with a cost of $60,000 to $100,000 per year. Costs of this magnitude, not to mention the emotional stress for patients and their families, are "catastrophic" by any standard. The experience of young patients with spinal cord injuries is similar. The tragedy of severe disability and dependence is equally painful for both the old and the young. It is, however, of potentially longer duration for the latter and in their cases strikes people who have had no opportunity to accumulate assets or retirement benefits.

III. REIMBURSEMENT OF COSTS OF REHABILITATION SERVICES AND PROGRAMS FOR CHILDREN WITH DISABILITIES

Federal and state regulations must recognize the need for comprehensive, rehabilitation and habilitation programs for children with chronic disabilities. Rehabilitation facilities specializing in providing services to such children can only do so if all therapeutic services are recognized as medically necessary and thus reimbursable. In addition, a high number of children with severe needs come from economically-deprived family environments. As a result, Medicaid regulations in particular need to be revised to support the provision of adequate, high quality services. This also applies with other payors who often resist paying for services other than those that are acute in nature. These children have long-term, chronic needs that have to be addressed.

Federal and state legislators and regulators must be made to understand that treatment for chronically ill children and young adults may be better and less expensive when given at home. It has been shown that many children dependent, for example, on medical technology, develop more normally when they are taken care of at home and allowed to interact with their family, friends, community and school. Also, home care is usually more cost-effective than hospital or institutional care. Studies by the Aetna Insurance Company have shown that home care costs range from 1/2 to 3/4 that of inpatient care. Indeed, savings from one baby born with breathing and feeding problems cared for at home is $40,000 per month. Aetna also has estimated $36 million in savings in 1985 by financing home care for 800 patients.

Despite the widespread acceptance of the home-care concept, public policy has been slow to respond. The vast majority of private insurers will not pay for home care for the chronically ill child, while the same care will be reimbursed in a higher-cost institutional setting. Further, a number of insurers provide a disincentive to home care by limiting costs for such care at a lower level than for inpatient care. Service needs are not being met because existing programs and private policies do not recognize nor cover them given the institutional bias that exists. While a more progressive approach has been adopted by a handful of insurers, it is clear the marketplace is not meeting the need.

Other barriers to the provision of necessary services include: inadequate reimbursement; federal and state regulations which do not require public and private payors to provide comprehensive rehabilitation and habilitation services; an uncoordinated patchwork of federal and state programs affecting this group (maternal and child health; Medicaid; Home and Community-Based Waivers under Medicaid; P.L. 94-142; Medicare; HMO qualifica--tions; etc.); inadequate community support services such as home-health care; and few long-term care options for this population.

IV. CONCLUSION

NARF recommends that the Committee support programs to move away from the institutional bias for rehabilitation services and needs of children with chronic disabilities. Services that can be delivered by home or through community-based organizations such as rehabilitation facilities, allowing children to live in as independent a setting as possible, are preferred. States should be allowed to provide home and community-based waivers without going through the cumbersome administrative waiver process. NARF believes it is critical that resources be spent on educating health care, education and human service providers on the complex needs of such children.

Further, NARF recommends that the Committee:

- o Remove the institutional bias in existing programs;
- o Examine existing federal and state programs to assure:
    - -- they provide coverage for rehabilitation and habilitation services for these patients,
    - -- coordination of existing programs or the parts of existing programs focusing on children,
- c Provide adequate insurance coverage for children with chronic disabilities as the Committee addresses the problem of those without health care coverage;
- o Include the problems of the underinsured, i.e., those whose existing policies:
    - -- do not cover rehabilitation or habilitation needs, or
    - -- whose benefits are exhausted because of the cost of serving children with chronic disabilities.

TESTIMONY OF
J.D. NORTHWAY, M.D.
PRESIDENT AND CHIEF EXECUTIVE OFFICER
VALLEY CHILDREN'S HOSPITAL
BEFORE THE
COMMITTEE ON FINANCE
UNITED STATES SENATE
TUESDAY, MAY 24, 1988

Mr. Chairman, distinguished Members of the Committee.

Thank you very much for allowing me the privilege of sharing some observations regarding children's health in this country as well as giving me the opportunity to offer one or two ideas which I feel must be addressed if we are really serious about solving the health care problems facing our nation's children.

I am a pediatrician as well as the president of Valley Children's Hospital in Fresno, CA, the only free-standing children's hospital in rural America. The children's hospitals across this nation are experiencing daily the results of the lack of basic health care available to our young citizens. We are all experiencing an increase in admissions at a time when general acute care hospitals are facing empty beds or actual closures. Why?

In part, it is due to the fact that 19 per cent or 10.2 million children in this country have no health insurance coverage. This is despite the fact that 50 per cent of these children come from families with working parents. Another reason may well be the alarmingly high rate of teenage pregnancies in the United States. One in 20 teenage women will give birth this year, many without ever receiving adequate prenatal care. Fourteen million women of child-bearing age are without health insurance. Most of these women are from a lower socio-economic status and are less than 18 years of age. Premature or low birth weight babies have a high mortality rate, and those who do survive are more likely to experience one of several life-long disabilities, such as autism, mental retardation, cerebral palsy, etc.

In our institution alone, 30 per cent of the days and 40 per cent of the costs are attributed to low birth weight babies. The average cost of caring for one of these youngsters is $2,000/day.

Many of these infants are born to single, teenage mothers with no insurance and no means of support. By neglecting to offer basic health care, we perpetuate a cycle of hopelessness. We continue to let teenage girls drop out of high school, continue to allow them to find hope in alcohol and drugs, and continue to bring children into a hopeless situation.

How can we break this cycle of poor, often uneducated young women getting pregnant, delivering premature babies who either die or need continued medical care? There is no simple answer to the problem, but simply providing good access to health care is a step in the right direction.

Access is a complex issue, and there are at least two conditions which must be met if a health care policy is to be successful. All health programs must address eligibility and reimbursement. Without appropriate attention to both these issues, any program is bound to be unsuccessful. Many states in this country have very narrow eligibility requirements to which are attached reasonable reimbursement rates. This kind of a program benefits a few, but leaves many without any coverage and very limited access. Other states, of which California is one, have reasonably broad eligibility requirements, but then reimburses providers inadequately. Access is denied in this situation because the program discourages providers, both physicians and hospitals, from participating.

Let's think for a moment about reimbursement. These discussions are often biased with the myth that all hospitals and all physicians are making too much money. In California, less than half the hospitals are Medicaid (Medi-Cal) providers. However, children's hospitals across the country are large Medicaid providers, often with percentages in excess of 30 per cent. Many of these institutions are fragile and financially vulnerable.

The physicians who provide the majority of the primary care to the children of this country are pediatricians and family practitioners with average incomes of $65,000. These are not the high rollers, but, on the contrary, are the physicians who are truly dedicated to caring for our young people.

I live in a state where there have been attempts to cut out-patient reimbursement by 10 per cent. Those are cuts in prenatal care; cuts in clinic visits for both acute care and wellness checkups; as well as office visits for the disabled. If this were to happen, poor mothers and their children would have less access to medical services unless it were a crisis situation. As we all know, crisis medicine is associated with hospital admissions and higher costs; costs which can be avoided if the family has good access to regular health care.

Adequate payment for primary health care makes good economic sense. Paying primary care providers appropriate compensation for well child and acute illness visits may well open up needed access for poor women and their children. Assuming that the child might visit the primary care provider 6-8 times during the first year of life, at $30/visit, we are spending $180-240/year. That is less than one-third of the average cost of one day's hospitalization and only one-sixth of the cost of one day in the neonatal intensive care unit. By short changing the primary care provider, we are denying access to the patient and running the risk of increasing the overall cost of health care. The cheapest way to treat illness is to prevent it from occurring in the first place.

In closing, I would like to suggest one way to provide good health care for children and reduce infant mortality. The children's hospitals of this country have long been recognized, along with the American Academy of Pediatrics, as real advocates for children's health. Why not use the children's hospitals as hubs to develop appropriate and effective networks for basic health care? Most already have in place physician referral systems that could be used to ensure this access. Many are developing networks with other hospitals, sometimes across entire states, as well as encompassing multiple states as is evidenced in Colorado.

The children's hospitals are a logical group to form a children's health care network in this country, with a full compliment of primary care providers and subspecialists when appropriate. And, perhaps most importantly, children's hospitals are trusted institutions, known for providing quality health care. Why not expand these centers to be gatekeepers for access? It seems like a natural place to start. And what better arena for the government to be assured of compliance and quality control than with the institutions responsible for the health of our future generations.

Finally, I ask you, why is it that a country that prides itself in being a leader in technology, that commands more military strength than any other nation in the world, and boasts of a sound financial base, lets its children suffer from inadequate health care?

Let's use our resources to insure the future. Children's hospitals may well be an insurance policy for our future, but we will need to pay the premiums as they fall due.

Thank you Mr. Chairman, I will be happy to answer any questions for the Committee.

STATEMENT

OF

TOKOS MEDICAL CORPORATION

RE: THE HUMAN AND FINANCIAL COSTS OF THE HIGH RATE OF PRE-TERM BIRTH IN THE UNITED STATES

WEDNESDAY, MARCH 25, 1988

Mr. Chairman and Members of the Committee,

Thank you for providing me with the opportunity to contribute to your examination of current programs and policies regarding children's health care. I represent Tokos Medical Corporation, a company that provides home uterine activity monitoring, perinatal nursing services, and tocolytic infusion therapy for women experiencing high-risk pregnancies.

Mr. Chairman and members of the committee, preterm birth is the cause of severe illness and death for tens of thousands of children each year. The Institute of Medicine reports that 6.8% of all births in the United States are low birthweight (<2,500 grams). Last year more than 250,000 low birthweight babies were born in this country. In 1983, the National Institute for Health Statistics reported over 5 million hospital days were required to care for preterm, low birthweight babies. The cost of this care exceeded $5 billion.

Children who are born too soon face terrible risks. Studies show that infants weighing 2,500 grams (5.5 pounds) or less are nearly 40 times more likely to die during the first 4 weeks of life than infants of normal birthweight.

Through advances in neonatal intensive care, many more of these infants are surviving. But thousands may live to face severe medical problems or even lifelong disabilities, including cerebral palsy, chronic lung and heart disease, blindness, hearing loss, epilepsy and learning disorders.

The human cost of pre-term birth is overwhelming, and so is the financial cost. One day in neonatal intensive care costs between $1,000 and $2,000, not including physician fees, lab charges, surgical procedures or medication. A premature infant may require up to 90 days of treatment in neonatal intensive care and experience frequent re-hospitalizations. The total cost of providing care for a very premature infant can easily exceed the lifetime limit on private health insurance benefits in the first year of life. In order to be eligible for Medicaid benefits, families must spend down until they reach the poverty level. A premature birth can mean financial ruin.

There are also emotional costs associated with pre-term birth. When a baby does not survive a pre-term birth, or lives to face chronic medical problems or disabilities, the parents must deal with intense feelings of grief, guilt, and frustration. Coping with the illness of a child - the prolonged and repeated hospitalization, financial pressures, the guilt and anger - puts enormous stress on parents and siblings. Studies have shown that very few marriages do survive that stress. Over 90% of the parents of chronically ill children eventually divorce.

The irony and the hope that the problem of pre-term birth presents to us is that many of these financial and personal tragedies are preventable. We know many of the risk factors associated with pre-term births are low birthweight. Those at the extremes of age are at greater risk, the poor and the poorly nourished are at risk, those expecting multiple births are at risk, those with a history of pre-term birth are at high risk. We are able to characterize many patients at risk for pre-term birth and we know that prenatal care and medical intervention can substantially reduce that risk.

It has been convincingly demonstrated that early prenatal care reduces the incidence of pre-term birth. And that patient education about behavioral and environmental risks will produce better outcomes. Technology has also evolved to allow sophisticated monitoring and prompt medical intervention when women experience the signs of pre-term labor. We have many of the resources we need to address the problem. What we lack is a concerted, national commitment to solving the problem.

A national effort to reduce the incidence of pre-term labor can succeed. In the early 1970's, Dr. Papiernick, a distinguished French perinatologist, launched the French Prematurity Prevention Program, a comprehensive national effort that included risk assessment, expanded patient education, and expanded provider education. The results were dramatic. From 1972 to 1981 the rate of pre-term birth in France declined from 8.2% to 5.4%. If a similar decline could be achieved in the US, it would mean 7,000 fewer pre-term births each year and over $100 million dollars annually in reduced health care costs.

The implementation of the French Prematurity Prevention Program was somewhat simplified by the existence of a national system for health care reimbursement. In the United States today, patients are covered by a patchwork of private and public health insurance programs with different policies regarding the reimbursement for preventive, prenatal care. And as we know, many patients have no insurance at all.

Even when coverage for preventive care is available, many patients simply don't seek help because they aren't aware of the risk of pre-term birth.

It is nonsensical that the system will readily reimburse $100,000 for neonatal intensive care, but balk at paying for a home perinatal nursing assessment or a community education program that could help prevent that catastrophic expense. Our focus has been on managing the consequences of pre-term birth and not enough on preventing the problem. That focus must change.

In the United States, health care costs now exceed 11% of the GNP. Our aging population has an increasing need for health care services. In this era of constrained resources and increasing demand, we must look for ways of making our national expenditure on health care more productive. Preventive care provided to women at risk of pre-term birth is one investment we are sure produces a healthy return. Studies show that every day a pregnancy can be extended means a day less spent in neonatal intensive, and a savings of $1,000 to $2,000 per day.

By learning more about which patients are at risk for pre-term birth, by making access to preventive services easier, by educating our population, we can reduce health care costs and improve the quality of life for literally tens of thousands of children each year.

Despite the advances we've made and are continuing to make in medical technology, despite our great prosperity, the rate of pre-term birth in the United States is not declining, it is growing. We rank behind most other developed countries in this area: behind Austria, Canada, Germany, Italy, Japan, Israel, the United Kingdom, and most European countries. Our record in this area is not one we can be proud of.

A nation is only as strong and capable as its people. Today many of our unborn children are at risk. Today our country is at risk. We must invest in the future, in our country's future. We must move quickly to address this problem.

Thank you for the opportunity to present these views.

California Association of Children's Hospitals

Testimony of the

WESTERN ASSOCIATION OF CHILDREN'S HOSPITALS

Delivered by

Blair Sadler

Before the

Senate Finance Committee

Regarding

Chronic Illness in Children

May 26, 1988

Mr. Chairman and members of the Committee:

My name is Blair Sadler, President and Chief Executive Officer at Children's Hospital and Health Center in San Diego, California. On behalf of the Western Association of Children's Hospitals ("WACH"), I appreciate very much the opportunity to present our views on the profoundly serious issue of chronically and catastrophically ill children. We commend you, Mr. Chairman, and all the members of this Committee for your strong interest in this issue and your commitment to the health care needs of children.

Each year, many Americans face the trauma of a catastrophic illness within their family. All too often, that family member is a child, and the emotional devastation is compounded by an overwhelming financial burden. Medical bills which run into hundreds of thousands of dollars precipitate the financial ruin of many of these families.

To illustrate the all too frequent catastrophic event, and the tremendous financial and emotional costs that can result, I would like to tell you the tragic story of Jessica. Jessica was a two-year-old female who was reportedly found in the bathtub, face down, a victim of child abuse. Initial evaluation revealed a severe injury to the abdomen and head. Her rectum was enlarged and her intestine was protruding. During transport to our Regional Pediatric Trauma Center, her heart rate decreased and her neurological status deteriorated. Her diagnosis at Children's Hospital revealed severe brain injury due to a lack of oxygen to the brain, rupture of the stomach, traumatic pancreatitis, hematoma of the uterus, tearing of the rectum, and multiple abrasions and contusions over the entire body.

Jessica's total hospital charges were $1,180,000, of which California's Crippled Children Services Program ("CCS") paid $426,000 and private insurance covered $430,000. Jessica's private insurance coverage, relatively speaking, can accurately be described as generous. Nevertheless, the hospital was left with a total contractual adjustment of $252,000 for just this one case. Unfortunately, this type of case cannot be described as highly unusual either.

Upon discharge, however, due to the high quality care she received, we are pleased to report that Jessica was active, and was alert, able to ride her bicycle, feed herself, and appeared to have normal intelligence. While she is profoundly deaf as a consequence of this traumatic experience, she can now hear at low ranges with a hearing aid as the result of twice-a-week speech and hearing therapy.

UNDER-INSURED CHILDREN

Under-insured families have policies which restrict the number of hospital days, cap the total amount payable for the insured's lifetime health care costs, or which have no maximum of "out-of-pocket limits."

Approximately 69% of children under age 16 have private health insurance upon which their families rely for economic support in the event of a catastrophic illness. Roughly 80% of these families obtain coverage through an employer-based group health insurance program. While some of these plans provide adequate protection against financial ruin, others provide only partial protection.

Approximately 12% of chronically and catastrophically ill children have government-sponsored health insurance, primarily through Medicaid coverage. However, Medicaid coverage varies widely across states in terms of benefits and eligibility requirements such that children may be eligible for coverage in our state but not in another.

UNINSURED CHILDREN

Presently, 10.2 million children, or 19% of this nation's children aged 0-16, are without any health insurance at all. Thus, this situation is not so much a problem of impoverished families exhausting their public assistance payments, but rather of uninsured families who comprise the "working poor".

These families have income in excess of Medicaid eligibility levels and yet are without access to, or cannot afford, private health insurance. Generally speaking, either the families do not have access to group health insurance because the employer does not offer it, or the coverage is prohibitively expensive. A recent survey conducted by Wyatt & Company reveals that less than one percent of surveyed employers offering Comprehensive Medical Plans adjust the employee's contribution for premiums to income and ability to pay. Only 24% of surveyed employers provide family coverage at no cost to the employee. Moreover, premiums can reach

$200 to $300 per month, which would represent 35 to 50% of the minimum wage worker's total monthly salary. This scenario places the worker in the impossible predicament of choosing between the purchase of health insurance or other basic necessities.

UNINSURABLE CHILDREN

Other children are simply "uninsurable" and they encounter difficulties beyond the lack of the availability and price of coverage. Typically, these children have "pre-existing" medical conditions which prevent them from obtaining private insurance coverage. These conditions include cancer, cystic fibrosis, diabetes, and other chronic disorders. According to the Wyatt survey, 31% of employers offering group health coverage restrict such coverage for pre-existing conditions. Frequently, these families must "spend down" their financial resources to a level where they can then become eligible for Medicaid, thereby placing a drain on already scarce public funds, as well as devastating the family's finances.

CALIFORNIA STATISTICS

Unlike the case with the elderly population, we are fortunate that the incidence of chronic and catastrophic illness in children is actually very low. We have compiled data based upon our experience in California, one of the few states which collects and distributes comprehensive public data on hospital utilization.

During 1984, there were 553,000 children age 0-14 hospitalized in California, excluding mental health admissions and Kaiser Hospital Admissions. This constitutes approximately 9.7% of the state's 5.68 million children under age 15. Of the 553,000 admissions, 93% incurred hospital charges less than $5,000. Only one-half of one percent incurred charges in excess of $50,000, yet this group had total charges in excess of $280,000, or 22% of the total charges of all 553,000 admissions. The average cost per child was upward of $100,000.

When viewed individually, such expenses are clearly catastrophic. However, if the financial risk for the cost of hospital care for all cases over $50,000 were spread across the entire population of children age 0-14, the cost would be roughly $4.55 per child per month. This is less than one-third of the cost of providing one day of public school instruction for one child in California. While this might not be an entirely satisfactory method of estimating the actual costs of care for these children, it certainly does illustrate the value of developing a plan wherein the financial risk and burden is spread across as large a population as possible.

We have also compiled data from California pertaining to the source of payment for care. For the

93% of cases where charges were less than $5,000, commercial insurers and Blue Cross plans were the payment source for approximately 45% of the children. The Medicaid share was approximately 33%. Individuals having no payment source other than their own funds represented a little over 6%. For those cases where charges were in excess of $50,000, commercial insurers and Blue Cross as a payment source fell to 32%, a 13% decline. Medicaid's share increased to 39% and self-payments remained fairly constant at 6.4%.

To the extent that public resources fall short, the burden of catastrophic cost falls on tertiary care institutions like children's hospitals. Specialty providers like children's hospitals and university medical centers handle approximately 25% of the volume in ordinary case, - the 93% of cases with per patient charges under $5,000. However, when one examines patients with charges in excess of $100,000, these same providers account for approximately 75% of the care rendered. We are not disputing the appropriateness of children's hospitals providing this care, since we are indeed best equipped to treat these children. We are concerned, however, with the extent to which this care is uncompensated. Children's hospitals, and for that matter other non-profit hospitals, due to increased economic pressures in the health care market, are no longer able to pass along these uncompensated costs to the private insurers. The issue of dealing with catastrophic illness and children is complex and may well defy comprehensive short-term resolutions. However, it is imperative that a plan for protecting these families from the economic and emotional ruin of catastrophic illness be developed, and that implementation of a multi-faceted remedy commence as soon as possible.

GENERAL RECOMMENDATIONS

We look forward to assisting this Committee with respect to such an initiative, and would suggest that any catastrophic health insurance system for children embody the following guiding principles:

1. A comprehensive program for children with catastrophic illness must be socially responsible. This means that benefits must be available to all children, regardless of the family's ability to pay, and benefits must be uniform across states. We must constantly remind ourselves that children are our hope for the future, and their proper care and treatment is our society's moral obligation.

2. Such a plan must be medically responsible. A successful plan must guarantee good quality care [provided at regional specialty referral centers] with extensive care management offered by qualified physicians, parents, and other members of the pediatric

care team. In addition, any new program must possess a system of accountability whereby a new, higher standard for what is achievable and expected in the care of very sick children is achieved. In pursuit of this goal, a national reporting system should be developed for catastrophic illness or injury cases where charges are over $25,000, whereby data on the incidence care and treatment of these children can be shared for the benfit of all.

3. Finally, and perhaps most importantly, given the current budgetary climate, a new program for children must be _fiscally responsible_. A keen eye must be kept on identification of costs and benefits, in particular the tremendous savings that can be achieved in long-term care through successful early treatment of these children. Existing reimbursement systems should be better coordinated in order to minimize duplication of effort and waste of scarce resources.

Mr. Chairman, thank you again for the opportunity to voice our concerns, and we look forward to working with you in the coming months.